DOCUMENT RESUME

ED 161 193 EC 112 321

AUTHOR	Doyle, Phyllis B.; And Others
TITLE	How to Help Your Child: A Guide for Parents of Multiply Handicapped Children.
INSTITUTION	Montgomery County Intermediate Unit 23, Blue Bell, Pa.
SPONS AGENCY	Bureau of Education for the Handicapped (DHEW/OE), Washington, D.C.
PUB DATE	[76]
GRANT	G007503427
NOTE	70p.; For related material, see EC 112 320
EDRS PRICE	MF-$0.83 HC-$3.50 Plus Postage.
DESCRIPTORS	Communication Skills; Counseling; *Educational Programs; Enrichment Activities; Equipment; *Learning Experience; Motor Development; *Multiply Handicapped; *Parent Child Relationship; Parent Education; Public Education; Resource Guides; Respite Care; *Self Care Skills; Severely Handicapped; *Special Services
IDENTIFIERS	Pennsylvania; Project TRAC

ABSTRACT

Developed by Project TRAC--Training/Resources Acquisition and Control, the three part guide is for parents of multiply handicapped children. Part 1 examines a public school training program for multiply handicapped children. Part 2 gives suggestions for activities that can make home life easier and at the same time provide learning experiences for the child. These activities include communications, lifting and carrying, positioning, motor skills, feeding, dressing, toilet training, and hygiene. In part 3 are many suggestions about where to go and what to do when parents need special help, including the names and addresses of special services in the Pennsylvania area, such as camping, parent groups, care and training for retarded adults, counseling and help with family problems, and home health care. Also in part 3 is information on special equipment, such as supports for sitting and lying, chairs, walking aids, and clothing. Special information on how to go about finding a baby sitter, obtaining a special car license plate for "handicapped only" and "no parking" privileges, income tax deductions, and planning for the future is also included. (PHR)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED161193

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Barton Proger

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC) AND USERS OF THE ERIC SYSTEM."

EC 112321

HOW TO HELP YOUR CHILD

A Guide for Parents of Multiply Handicapped Children

Phyllis B. Doyle
Jeffery N. Grotsky
Lester Mann
Paul R. Wagner
Peter Boardman

The work presented or reported herein was performed pursuant to a Title III, Section 306 Grant (Grant number G007503427, OE Entity number 1236050261A1, Project number 516AH50487) from the United States Office of Education, Bureau of Education for the Handicapped. The Bureau encourages expression of ideas. However, the opinions expressed herein do not necessarily reflect the positions or policy of the USOE or BEH, and no official endorsement by either should be inferred.

ACKNOWLEDGEMENTS

This Guide was prepared by *Project TRAC—Training/Resources Acquisition and Control.* Project TRAC was funded by the federal government under the title of *Pennsylvania Training and Demonstration Center for Severely and Profoundly Retarded Children.*

The Project has received the support of the Pennsylvania Department of Education. With special thanks, we would like to acknowledge the following people:

Dr. Gary J. Makuch
Director, Bureau of Special & Compensatory Education
Dr. William F. Ohrtman
Chief, Division of Special Education
Mr. Robert C. Warkomski
Advisor for Speech & Hearing
Division of Special Education

The Montgomery County Intermediate Unit has provided support and facilities for the Project. For this we are indebted to Dr. Dennis Harken, Executive Director of the Intermediate Unit, and the members of the Intermediate Unit Board of Directors.

We would like to especially thank Mr. Jerome T. Potter, Supervisor of Special Education, and the following staff members of the Center for Developmental Education which is administered by the Intermediate Unit:

Miss Kathy Bolger
Teacher
Mrs. Jennifer Favata
Teacher
Miss Kyle Taylor
Teacher
Mrs. Ildiko Gardner
Occupational Therapist
Mrs. Margo Orlin
Physical Therapist
Miss Nancy Lucas
Teacher Assistant
Mrs. Susan Wetzel
Teacher Assistant

We would also like to thank the children in classes for the multiply handicapped in Montgomery County and their parents.

Finally, we extend our appreciation to Mrs. Patricia Gavin, who served as Secretary on the Project.

CONTENTS

Introduction 4

Part I How to Help Your Child Get the Most Out of School 5

Part II How to Help Your Child at Home 19

Communications 20
- Gestures
- Speech

Lifting and Carrying 22

Positioning 24
- Lying on His Stomach
- Lying on His Side
- Sitting

Motor Skills 29
- Turning His Head
- Lifting His Head
- Reaching
- Rolling
- Sitting
- Leg Movement

Feeding 32
- Positions for Feeding
- Helping Him to Chew and Swallow
- Teaching Him to Feed Himself

Dressing 37
- Clothing
- Dressing Your Child
- Teaching Dressing

Toilet Training 41

Hygiene 43
- Washing
- Dental Care
- Skin Care
- Hair Care

Part III How to Find Help for Your Child — Services, Equipment and Information 47

Special Services 48
- General Help
- Camping
- Parent Groups
- Care and Training for Retarded Adults
- Counseling and Help with Family Problems
- Home Health Care
- Clinic and Hospital Care
- Information and Other Services— Local and State Organizations

Special Services *(continued)*
- Information and Other Services— National Organizations

Special Equipment 56
- Supports for Sitting and Lying
- Chairs
- Wheelchairs
- Car Seats
- Walking Aids
- Eating Aids
- Toilet Training Aids
- Clothing
- Hygiene Aids
- Hospital Equipment Stores

Babysitting 64
- Finding a Babysitter
- Information for the Babysitter

Transportation 66

Income Tax Deductions 67

Planning for the Future 69
- Death of Parents
- Wills and Trusts
- Insurance
- Social Security
- Legal Help

INTRODUCTION

This Guide has been written to help you help your child.

The information it contains is based on three questions often asked by parents of multiply handicapped children. What is the public school doing to help my child? What can I do at home to help my child? And where can I find the special help my child needs? These three questions are answered in the three parts of this Guide.

The first part of this Guide describes a public school training program for multiply handicapped children. In Pennsylvania, handicapped children of school age have a right to a free public education. This means that the schools must provide suitable training programs for these children. We have described one of these programs to show you how they can help multiply handicapped children.

The second part of the Guide explains how you can help your child at home and how to teach him to do things for himself. For example, there are hints on how to feed your child, how to toilet train him, and how to teach him to dress himself.

The third part outlines the information you may need in order to find help for your child. For example, it includes information on how to find a qualified babysitter, what tax deductions you can claim, and how to make special equipment.

This Guide is only a beginning. It does not contain all the information you need to train and care for your child. However, it can be a base of information on which you can build.

So, after you read the Guide, talk to your child's doctor and his teacher and therapists at school. Talk to the people at the local agencies for the handicapped. And talk to other parents of multiply handicapped children.

You should keep in contact with these people and work with them. Their assistance and the information in this Guide can help you help your child.

PART I
HOW TO HELP YOUR CHILD GET THE MOST OUT OF SCHOOL

You can help your child to get the most out of his school training program by understanding what that program is all about.

In Part I, we will be looking at a public school training program for multiply handicapped children. You will see what the children do during the day —from the time they get off the bus in the morning until the last activity of the day. To get a really clear idea of what *your* child does at school, talk to his teacher. She can tell you about his training program and how you can help. Your child's training will be most successful when you and his teacher work together.

6

7

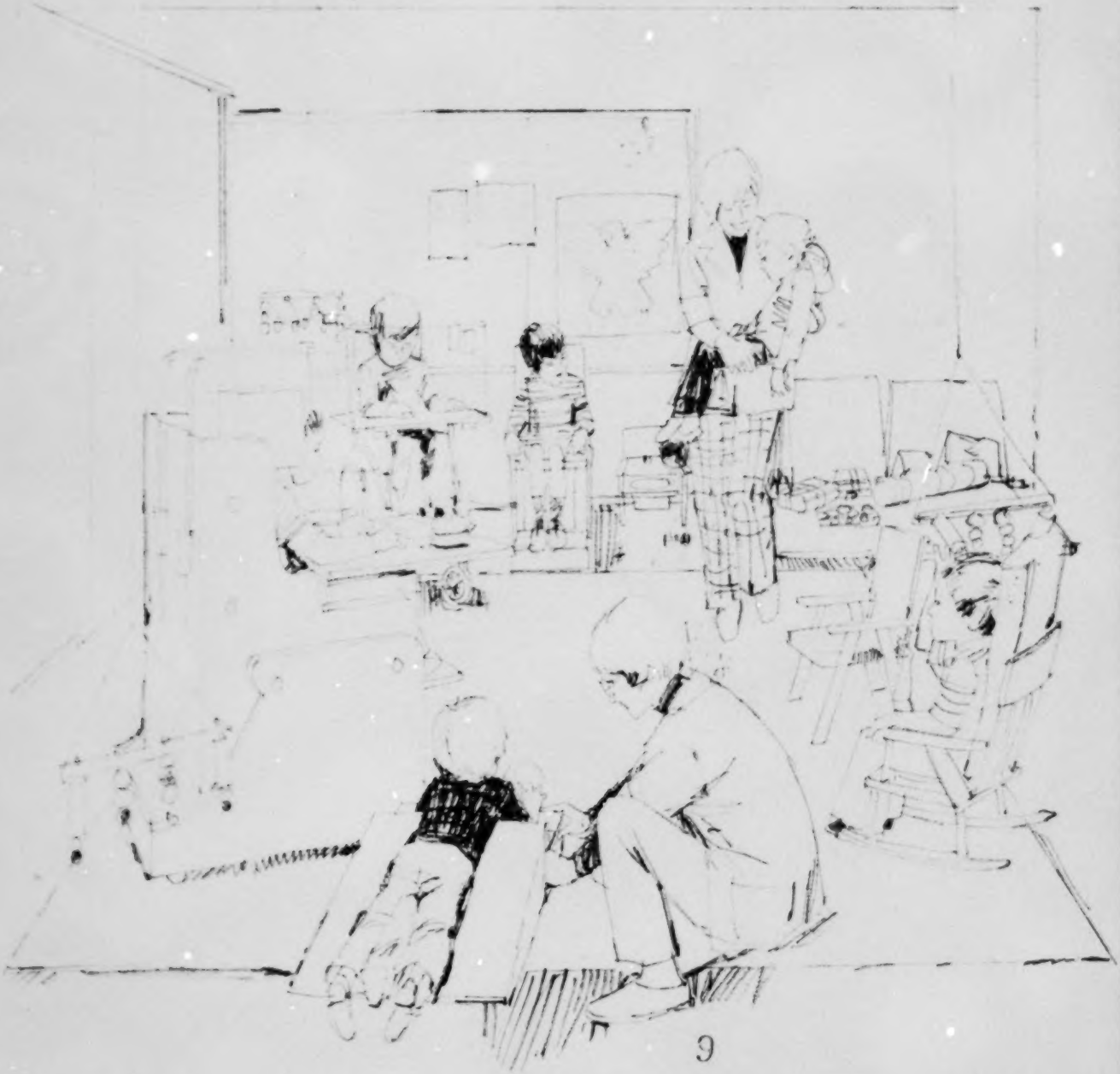
"Benjamin! Good morning!"

Benjamin grins and looks out the window of his minibus. A teacher slides open the side door and reaches in to help him unbuckle his seatbelt and shoulder strap. She takes him by the hand and helps him step down from the bus.

Another teacher climbs into the bus and unbuckles the straps around Eileen, who sits in a padded plastic carseat. Eileen rides in the carseat because she is severely handicapped and can't sit up in a regular bus seat. The teacher cradles Eileen in her arms and carries her into the building.

You can help your child get the most out of the school program if you know something about the training which goes on in his classroom every day. There will be very few children in his class —no more than six or seven. This allows the teacher and her assistant to give a lot of individual attention to each pupil. Your child's class is also arranged so that the children in it can learn from each other. For example, it is helpful for a child who is beginning to walk to be with other children who can already walk. He will watch and learn from them.

Many people contribute to a successful classroom experience for your child. The trained teacher has knowledge of your child's abilities and needs, and she calls upon speech, vision, physical and occupational therapists to help your child overcome his problems and learn new skills.



As the teacher carries Eileen into the classroom, she checks her diapers and notices that the child is wet. So she lays Eileen on a padded tabletop and begins to change her diapers.

Placed around the classroom is furniture specially suited to the needs of the children. A little boy who has difficulty holding his head up sits in a wheelchair with a headrest. Another boy sits on a potty-chair with a seatbelt to keep him from falling off and armrests to help him sit up.

Helping the teacher with the children is the teacher's assistant. "Here we go, Michelle," the assistant says as she picks up the girl and lays her on her stomach on a "wedge" — a large wedge-shaped piece of foam rubber covered with cloth. When Michelle is placed in this position, she can learn to control her body. Then she can lift her head and look at her surroundings.

During the day your child works on activities to help him learn how to take care of himself. Included are such things as holding a spoon, picking up his head, using the toilet, and pushing his arm through a sleeve.

Since your child's class is small, the teacher is able to plan a training program just for him. To do this, she uses reports from doctors and the school psychologists. These reports often give information about your child which can be used to understand him better. More importantly, your child's teacher tries to understand what he does and why he does it by carefully watching his behavior. These are the first steps in developing a training program for your child.

12

Two little girls sit at a small table with the teacher between them. Today the teacher is helping them learn how to touch a spoon. The teacher places a cup and a spoon on the table in front of Eileen.

"Eileen, touch spoon — touch spoon." At first Eileen looks away from the table. Then she looks back at the spoon and slowly reaches out and touches it. "Good girl, Eileen!" The teacher rewards Eileen with praise and by popping a piece of potato stick into her mouth. The teacher asks Eileen to touch the spoon a few more times and rewards her for trying. Eileen's progress is then recorded on her chart.

Next, the teacher places a cup and spoon on the table in front of Jamie. "Jamie, touch spoon." Jamie reaches out and touches the spoon. "Good girl. Good, Jamie!" Up until today, the teacher had been giving Jamie a little bite of cereal as a reward for touching the spoon. But today she wants to see if Jamie will do it without the food reward. So she just gives the child a word of praise as a reward. The teacher says, "Jamie, touch cup." Jamie looks up at the teacher, then at the table. She slowly reaches out and touches the cup. "Good, Jamie! Good girl!"

The program of training that the teacher sets up for your child is based on objectives. An objective is a goal that the teacher sets for your child. For example, an objective for your child might be "to pick up a cup of juice, bring it to his mouth without spilling it and drink the juice."

To make it easier for your child to reach the objective, the teacher breaks it down into smaller steps. She teaches your child one step at a time. For example, she might teach him to just pick up the cup. As he learns each step, she helps him put it together with what he has already learned. Finally he is able to do the whole thing —he has reached the objective.

During an average day, your child's teacher might work with him on several different objectives. One objective might be in the area of Feeding, another in Toilet Training, another in Communication, and so on. As the teacher works on each of the objectives, she keeps a careful record of your child's progress. The teacher —and you— can look at this record and see how well your child is doing.

13

"O.K., Marie. Let's have something to drink." The teacher places Marie's hands around a plastic two-handled cup. "Marie, drink." Marie lifts the cup to her mouth and takes a drink of apricot juice —one of her favorites. "Good! Good drinking, Marie."

The teacher has been working with Leonard and Marie on the objective of drinking from a cup for about three months now. Leonard is not as far along as Marie, but the teacher works with each child as an individual, and his improvement is only compared to his past work, not to other children's.

Sitting behind Leonard, the teacher takes his hands in hers and helps him hold the cup. "Leonard, drink." Holding his hands on the cup, the teacher lifts it to his mouth and tips it slightly. Then she watches to see if the juice is going into Leonard's mouth. As Leonard begins to sip, she takes away her hands so that he is holding the cup by himself. Yesterday, when the teacher tried this, Leonard dropped the cup and juice went all over his bib. But today, he holds the cup to his lips and goes on sipping the juice. "Good job, Leonard!"

14

Although your child spends most of his school day with the teacher and her assistant, speech, vision, physical and occupational therapists may also work with him.

The speech therapist tries to help your child learn how to talk. First, she trains him to use his lips and tongue to make sounds. Then she helps him put the sounds together into words. Like the other therapists, the speech therapist works with the teacher to develop a special program for your child.

If your child is blind, the vision therapist can train him to use his other senses. She may, for example, teach him to know food by smell or touch, and to identify objects by the sounds they make. If a child is not blind but has poor vision, the therapist can help him learn to focus on objects or to follow moving objects with his eyes. This kind of training helps him learn to do other things like feeding or dressing himself.

The physical therapist can help your child learn how to control his body. She can show your child's teacher exercises to strengthen his muscles and help him use them more effectively. She helps the child learn to sit up, crawl, walk and use stairs. She also checks braces and wheelchairs to make sure they are just right for him. When your child begins to outgrow his braces or wheelchair, the therapist can also give you advice about changes that need to be made or new equipment you might need to buy.

The occupational therapist can help your child learn how to take better care of himself. She might work with him on things like brushing his hair or feeding himself. She helps him learn to control the movement of his body. And she might use games to help your child learn to follow directions better, to finish what he starts, and to use his eyes and hands better.

The school also has a social worker who will help you understand better what goes on in the school. She will meet with you alone or with a group of other parents, and will tell you about the school program and what other kinds of help you can get for your child.

Probably the best way for you to understand what your child is doing in school is by meeting with his teacher. Regular meetings with the teacher will help you to become more involved and more familiar with your child's progress and problems at school. Your child's teacher can also give you some ideas about how to help him at home.

When you come in for a parent-teacher meeting, it might be helpful to bring along any questions you might have about your child's behavior, or any ideas you might have about his training. By preparing for your conference in this way, you will be better able to work with his teacher to help him.

15

16

The door to the classroom swings open and Mr. and Mrs. Eckert walk in. Miss Berger, the teacher, sees them, smiles, and points toward a couple of chairs. At the moment she is busy with their son, Benjamin. "Benjamin, touch head." She places her hands on his and guides them to his head.

The parents watch as Miss Berger moves around the circle of children seated in the middle of the room. This is "circle hour," the last activity of the day. Today, during circle hour, the children are being taught the parts of the body. Each practices touching his head, ears or nose. Finally, circle hour ends with a song: "If you're happy and you know it, clap your hands..."

The teacher and her assistant help the children into their coats and onto the bus. Then the assistant sits down to play with Benjamin while the teacher meets with his parents. She lays out on the table several charts that show Benjamin's progress over the last three months.

Miss Berger points to one of the charts. "You see, he can pick up finger foods and put them in his mouth, which is really an improvement since the beginning of the year."

Mr. Eckert agrees. "We've noticed the same thing at home. And it's made dinner time a little easier for us." Mrs. Eckert breaks in, "Do you think he's ready to spoon-feed himself?"

"I think we may be ready to start working with him on it," Miss Berger says. "But it can be slow going. Maybe we'll just start getting him used to holding the spoon."

"How about dressing himself?" Mr. Eckert asks.

Miss Berger shakes her head and smiles. "Well, we haven't had much luck there, have we?"

"No," says Mrs. Eckert. "But I wanted to tell you something. Last week, as I was taking his coat off, he helped me by pulling his arm out." She looks at her notebook. "It was twice last week, in fact. Wednesday and Friday."

Miss Berger raises her eyebrows. "Really? I'm glad you told me because I hadn't noticed anything like that at school. I'll see if I can get him to pull his arm out when I take his coat off at school."

The discussion moves from dressing to toilet training and then to Benjamin's most recent check-up at the dentist. Finally, all the items on Mr. Eckert's list are checked off. He looks up at Miss Berger and says, "Well, I think that's all for now —do you have anything more for us?"

"Yes, I want to thank you both for working with me on the training. It really helps me... and Benjamin."

PART II
HOW TO HELP YOUR CHILD AT HOME

You spend a large part of your day moving your child, feeding him or dressing him. There are ways of making these activities easier for you and him. At the same time, these activities can become real learning experiences for your child.

In Part II, we will be making suggestions about these activities. Our suggestions are general and may not be exactly right for your child. But, you can also get help from your child's teacher, therapists and doctor. Just like you, they are trying to help your child.

COMMUNICATION

The more you communicate with your child—that is, the more you talk and gesture to him—the more likely he is to learn how to communicate with you.

Even though he may not seem to respond, you should still talk to your child and tell him what you are doing as you do things around the house—from cooking dinner to watching a football game on television. You should also talk to him while you are doing things together. Use words, gestures, actions and even facial expressions to help him begin to understand what is going on around him.

Your child's teacher and therapists can give you suggestions on how you can help your child learn to communicate. Also, we have provided some suggestions that will help.

Gestures

Your child lets you know what he feels, thinks and wants in many different ways. Talking is not the only way that you and he can communicate. For instance, you should try to teach your child to use gestures.

Begin this training by teaching your child to use a simple gesture that you know he can do. For example, to teach your child to let you know he wants to

be picked up, raise your arms and say the word "up." If your child imitates you by raising his arms, pick him up and reward him. Show your child that you understand and appreciate what he has done. If he doesn't raise his arms on his own, help him raise them and then say "up" and pick him up. By making certain that you use the same gesture every time, you will keep your child from becoming confused. If your child starts to raise his arms when it is time to go to dinner or go outside, pick him up quickly and reward him. He is showing that he understands the connection between the gesture of raising his arms and getting picked up.

Speech

While you are helping your child use gestures to communicate, you can also teach him to use sounds or words.

Talk to your child during the day on a regular and informal basis. It will help him to become better acquanited with everyday conversation. Also, remember that it is not only what you say to your child that is important, but how you say it as well. You can use the tone of your voice to communicate how you feel to your child. If you're sorry or if you are pleased, your words *and* the tone of your voice will let him know how you feel.

You can use your conversations with your child to teach him words. For example, when you give him something to eat, you can make it a learning activity by saying the word "eat" slowly, clearly and directly to him as you help him eat. Whenever possible, try to get him to say words after you say them. This will help him to connect the word "eat" with the activity of eating. Even if your child cannot say the whole word correctly, you should reward him if he shows you that he is trying to say the word.

Let's try other examples. Say "coat" as you take your child's coat from the closet. Repeat "bath" as you place your child in the tub, or "car" as you sit him in the car. By saying the words at the right times and by repeating them slowly and clearly, you help your child begin to connect them with the ideas or objects they represent.

During the day, you will probably have many chances to use words that tell your child what you are doing or what is happening. You can often help him understand more clearly what is going on by using gestures that give extra meaning to the words you use. For instance, if you say the word "tall" you can show what you mean by stretching your arm in the air. However, you should use the same gesture for the same word all the time. This way you not only make your child familiar with both the word and the gesture, but you also avoid confusing him. It may also help if, when you talk to your child, you move his body to help him understand what the word means. Hold his hand out in the rain when you say the word "rain." Or guide his hand to pet a dog as you say "dog."

Reading List

If you would like to learn more about communication, you might want to read the following:

Kent, L.R. *Language acquisition program for the severely retarded.* Champaign, Ill.: Research Press, 1974.

Schiefelbusch, R.L., (Ed.). *Language of the mentally retarded: NICHD —Mental Research Centers Series.* Baltimore: University Park Press, 1974.

LIFTING AND CARRYING

There are probably many times during the day when you lift or carry your child. As he grows and becomes heavier, this lifting and carrying naturally becomes more difficult. Because you probably have to lift your child more often than most parents, it's important that you know how to lift him correctly and with the least effort.

Although carrying your child seems like a simple activity, planning is important. Remember to clear your walking path before you lift him. And make certain that there is nothing on the chair or in the area to which you plan to take your child. If you plan to sit your child in his wheelchair, it makes good sense to remove the tray table and lock the wheels before you lift him.

To lift your child, put him into a sitting position. Bend his head and shoulders forward, and bend his legs at the knees. Putting him in this position will keep him from becoming stiff. The more relaxed he is, the easier he will be to pick up.

Different children should be lifted in different ways. Your child's teacher or therapists can give you special advice about your child. However, here are some general points you should remember:

 1) Kneel down as close to your child as

possible so that you do not have to reach out to him when you pick him up.

2) Keep your back straight and hold him close to your body as you lift him.

3) As you stand up, don't twist your body—you might hurt your back. Once you are standing up, you can then step around towards a different direction.

While you are carrying your child, try not to lean to one side. When you turn, don't twist your body. And hold him close to you so you won't lose your balance or twist your back.

While there are several different ways you may carry your child, here are two possible ones:

1) You can carry him facing you with your hand under his buttocks and with your hip between his legs. This is an especially good position for a child who becomes stiff when you carry him because it helps him to keep his legs apart and bent. Once he becomes used to this position, he may become more relaxed.

2) You can also carry your child while he is in a sitting position and is looking forward. Simply place your hands behind his knees and let his back rest against your body as you carry him. This carrying position is especially good if your child is floppy.

Just as there are correct ways to carry your child, there are some things that should not be done when you carry him. First of all, do not hold him under his arms so that his arms and legs dangle. This may make your child stiff and more difficult to hold. Secondly, don't hold him around the waist when you carry him. His head may have a tendency to push back and his legs may become stiff, making him harder to handle.

Reading List

If you would like to learn more about lifting and carrying, you might want to read the following:

Cooper, J.& Morehouse, L.E. *Assisting the cerebral palsied child: Lifting and carrying.* United Cerebral Palsy Assn., 1953.

Finnie, N.R. *Handling the young cerebral palsied child at home.* New York: E.P. Dutton & Co., 1975.

Robinault, I. (Ed.). *Functional aids for the multiply handicapped.* Hagerstown, Md.: Harper & Row, 1973.

Svirsky, H.S. *The severely involved child: maternal backache.* Clinical Orthopedics, 1966.

POSITIONING

A multiply handicapped child has trouble controlling his muscles. The result may be that he becomes very stiff or, sometimes, just the opposite—very floppy. Because he cannot control his muscles, even simple things may be very hard for him to do.

He might be unable to sit up by himself in a chair. Or, when he tries to reach out for something, his movements may be awkward and jerky so that he cannot reach what he wants.

You can help your child control his muscles better through good positioning. When his body is positioned or arranged in a certain way, he will have more control over himself and his actions.

In this section, we will describe several of the positions that you should use with your child. It's important to become familiar with these positions. You can prevent red marks, bedsores, stiffness and other problems by changing your child's position often.

When you do position your child, keep in mind that you need to work with his whole body. That's because each muscle connects with other muscles and they all move together. So, for example, if he cannot control his arms and

shoulders, he may also have problems sitting up. And when your child reaches for something with his hand, he may not be able to keep his head from turning. So, even if you are trying to help him control his head, you must keep in mind that you have to correctly position his whole body.

In the following drawings and descriptions, we will try to show several different ways you can position your child. Of course, every child is different. Your child has certain abilities and handicaps that other children do not have. And you should talk to your child's teacher, therapists and doctor about what special positions are best for your child. But you can use the following information as a starting point.

Lying on his stomach

The two drawings show the correct and incorrect ways to position a child on his stomach.

Using a sloping wedge or a roll under your child's chest can help him keep his head up while he is lying on his stomach. The Special Equipment Section has simple instructions on how you can make wedges and rolls. Lying on a wedge can also make it easier for your child to use his hands and see what he is doing. This position will also help him develop better head control.

When your child is on his stomach and lying on the wedge or roll, try to get him to hold himself up on his elbows and forearms. His head should be straight and centered between his arms while he is doing this. If your child does not hold himself up on his elbows, try placing sandbags along the outsides of his arms to hold them in the correct position. If you find your child's legs closed tightly while he is on his stomach, or if they are crossed, a roll placed between his legs will keep them apart.

Sometimes, your child's hands might close up into fists while he is on his stomach. When this happens, rub the

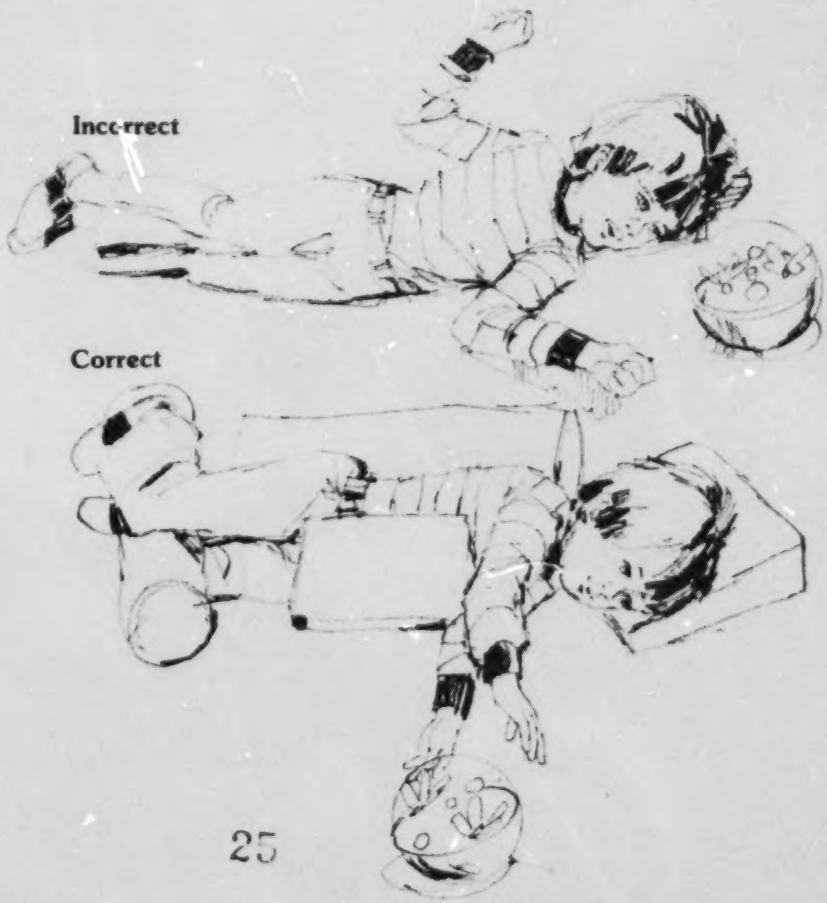
backs of his hands to see if the fingers start to relax and open. If this does not work, straighten out his arms at the elbows and bend his wrists so that the palms come toward the forearms. Your child's fingers should loosen. Then place your own hands inside of his and very gently begin to open his fingers. If they still tend to close up, even after you have helped him to open them, a small toy or soft object placed in his open hands will help keep them open.

Lying on his side

The two drawings show the correct and incorrect ways to position a child on his side.

When your child is lying on his side, use a pillow or sandbag to hold his head forward and to raise it up. Sandbags or cushions can be placed behind his back and in front of his stomach to keep him from rolling over. You can use a pillow or roll to keep his legs apart while he is lying on his side. And remember to try to keep his legs slightly bent. There is information in the Special Equipment Section on how to make rolls and sandbags.

It is important that your child doesn't always lie on the same side. Change him to the other side as often as you can to keep him from becoming stiff.



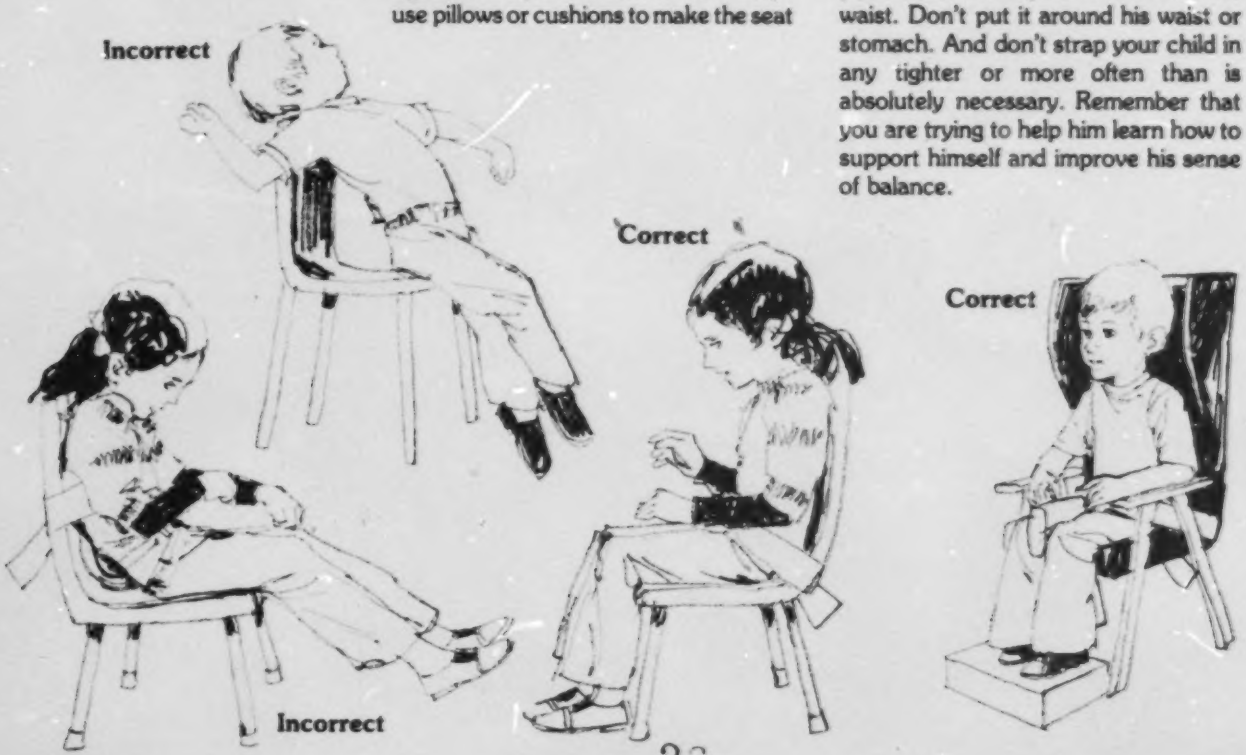
Sitting

The drawings show the correct and incorrect ways of sitting in a chair.

Your child should sit in a chair that provides support for his body—especially his head, arms and legs. Different types of chairs are described in the Special Equipment Section. But whatever kind you decide to use, here are several points you should remember:

1) The seat of the chair should be the right size for your child. You can always use pillows or cushions to make the seat fit better if it is too large. When your child is sitting, his bottom should be pushed all the way to the base of the chair and his knees should just bend comfortably over the edge of the seat.

2) When you use a belt or strap to keep your child from falling, it should be placed across his pelvic area below his waist. Don't put it around his waist or stomach. And don't strap your child in any tighter or more often than is absolutely necessary. Remember that you are trying to help him learn how to support himself and improve his sense of balance.



3) While sitting, your child's arms should be relaxed, not stiff or dangling at his sides. A tray attached to the front of his chair can help. It will give his arms extra support and, at the same time, will provide him with a place to play with his toys.

4) If your child's legs tend to cross while he is sitting, you should use something to keep them separated. If you keep them parted at the thighs, it will help your child to sit back correctly in the chair and keep his feet flat on the floor.

5) If your child's feet do not rest flat on the floor while he is sitting, you can place a box under his feet to give them the proper support. Without this support, his feet may dangle and he may become stiff and slip out of the correct position.

6) Your child should not always sit in the same chair. It can be helpful for your child to sit in different types of chairs such as beanbag chairs, armchairs and even inner tubes and cut-out cardboard boxes. You will find suggestions for how to use some of these in the Special Equipment Section. But no matter where your child sits, make sure that his body is supported by whatever pillows, rolls, boxes or belts that he needs.

If your child is learning how to sit by himself, let him first sit on the floor with his back against the wall for support. After he is able to sit up like this, then begin to let him sit up on the floor, or on a chair or stool *without* a back. In this way, he can practice balancing himself.

Your child should not spend all of his time sitting. If your child stays in any one position day after day, he will become stiff and may develop sores or more serious problems. So, for a change, let him spend part of each day on the floor, supported by rolls or wedges if he needs them.

Reading List

If you would like to learn more about positioning, you might want to read the following:

Finnie, N.R. *Handling the young cerebral palsied child at home.* New York: E.P. Dutton & Co., 1975.

Hart, V. *Beginning with the handicapped.* Springfield, Ill.: Charles C. Thomas, 1974.

MOTOR SKILLS

Motor skills include many things a child does—head turning, jumping, throwing a ball. This section will give you information you can use to help your child improve his motor skills.

Before you work with your child on improving his motor skills, you should become familiar with correct *positioning* which was described in the section before this one. Correct positioning helps your child to control his body, and to move more easily. Therefore, you should be certain that your child is correctly positioned before you begin to help him with his motor skills.

Turning his head

It is very important for your child to learn to turn his head. Turning his head will help him develop and use muscles he will need to lift his head. First, help your child turn his head from one side to the other while he is lying on his stomach. Ring a bell or call his name when you are behind him to make him turn his head to see where the sound is coming from.

Lifting his head

If your child is able to turn his head, try to get him to lift his head straight up and to hold it up while he is lying on his stomach. To help him do this, place a roll or wedge under his chest. This will usually make him more relaxed and is the best position for him to be in while he is learning to raise his head. To get him to raise his head, try to catch his eye by moving a large colorful toy, a mirror or noise-maker in front of him. Once he is looking at it, raise the toy so that he will have to lift his head to follow it. When your child is lying on his stomach with his head up, he can look at what is going on around him and learn from it.

There are a few important things you should know about helping your child lift his head. If he turns his head to one side as he lifts it, he should be helped to pick it straight up. Also, make sure that he holds himself up on both arms. If he doesn't pick his head up, try rubbing firmly up and down on the back of his neck. This helps some children to raise their heads.

Reaching

While your child is still on his stomach, encourage him to reach out and hold on to toys. Toys with handles are the best for this. For example, you might use a rattle with a large handle. Also, sponge balls or soft toys are easy to pick up and hold. At times, you should use things with your child that move easily when he touches them. For example, let him play with a ball. If he sees it move when he touches it, he may want to reach for it again. If it's fun for him, he will practice reaching more often.

You can also try using a piece of yarn with loops at each end to get your child to practice reaching. You hold one loop and your child holds the other. Gently pull the yarn toward you. By simply holding on to the other end, your child will be learning a movement that is very much like reaching.

As your child begins to reach for things by himself, you should give him chances to practice reaching in different directions. Have him reach for objects above his head, to the side of him, or far in front of him. Try to make a game out of this by using things that he likes to play with. The more pleasant the game is, the harder he will try to reach.

Rolling

Rolling can make it possible for your child to change his own position. If he is tired of lying on his side, for example, he can roll over on to his stomach. Also, if he learns to roll very well, he will be able to move from one place to another by himself.

You can start this training by teaching your child to roll from his stomach to his back. He should begin the roll with his head and shoulders while his legs are bent only slightly. Don't let your child attempt to roll when he is curled up in a ball. This could become a bad habit which will keep him from learning the right way to roll.

You can teach your child how to roll any time during the day by making rolling a part of his daily routine. For example, try to have your child roll over once before you get him out of bed each morning.

Sitting

Help your child hold his head up while he is sitting. If he does hold his head up on his own, give him a lot of attention or praise to make him feel good for trying. If you usually use pillows or other objects to support his head, take them away once in awhile so he will have to learn to hold his head up on his own.

To help your child learn how to sit, place him so that he is leaning against a wall with his legs out in front of him or crossed Indian-style. Get him to hold himself up by placing his hands on the floor on either side of his body. You can help him practice sitting by pushing him off balance slightly so that he learns to correct his position and balance himself.

Leg movement

Encourage your child to move his legs often. For instance, while diapering him, lift both his legs in the air, bend his legs at the knees and then straighten them. Do this several times. Or, while he is sitting in a chair, you can play a "marching" game with him, helping him to lift first his left foot and then his right foot up and down. As you move his legs, you might even say, "left-right-left-right." Try to think of other ways to give your child practice moving his legs, like kicking a ball or pushing his feet into socks or pants while dressing.

Reading List

If you would like to learn more about motor skills, you might want to read the following:

Finnie, N.R. *Handling the young cerebral palsied child at home.* New York: E.P. Dutton & Co., 1975.

Hart, V. *Beginning with the handicapped.* Springfield, Illinois: Charles C. Thomas, 1974.

FEEDING

One of the first things that parents want their child to learn is how to feed himself. But eating is not a simple activity. For your child to feed himself, he must be able to sit up, pick up a fork or spoon, scoop up his food, put the food into his mouth, chew it, move it around with his tongue and swallow it.

If your child is learning to feed himself at school, ask his teacher how she is training him and what things seem to work best. She should be able to give you advice about what you can do to further help your child at home. While you are talking with her, find out how you can keep a record of his improvement as you work with him. This will let you see how well he is doing. Also, you can use the record to show the teacher what is happening at home. Let the teacher know about any things that work for you at home. Your child will benefit when you share your information.

This section will give you some ideas on how you can position your child so he can sit up to eat. And it gives you some hints on how to help him chew and swallow correctly. It also offers ideas about how you can train your

child to feed himself. For other suggestions, you should talk to your child's teacher or therapists, or read some of the material listed at the end of this section.

Positions for feeding

The first step in feeding your child is to position him correctly. The best position for feeding is a sitting position. Hold the child in your lap, or sit him in a chair, so that he is sitting up with his head slightly forward. It may be necessary to put something behind his head to keep it from pushing back. Or, you might have to hold his head so that it will not fall forward. With his head in the correct position, he will be able to chew and swallow much better.

It is not a good idea to put the food into your child's mouth when his head is tipped back. This is called "bird-feeding." Not only will birdfeeding keep him from learning how to swallow correctly, but he might take the food into his lungs rather than his stomach.

Helping him to chew and swallow

Three-finger jaw control is a way to help your child chew, bite and swallow. What you are really doing is helping your child eat better by controlling the movement of his jaw or lips with your fingers. Because he may take awhile to get used to this, begin by using it only for short periods of time. The drawings show you how to hold your hand for correct three-finger jaw control.

If you are sitting beside your child, with your arm around the back of his head:

1) Put your middle finger under his chin.

2) Your index finger is placed on the front of his chin.

3) Use your thumb on the side of his cheek to control his head.

If you are sitting in front of your child:

1) Your middle finger is placed under his chin to help you to control his jaw.

2) Your thumb is placed on the front of his chin, where it can help you to close his lips and control his jaw.

3) Your index finger is placed along the side of his cheek to control his head.

Three-finger jaw control will help you teach your child how to eat better while you are feeding him. But you might also practice jaw control on your child at other than feeding times so that he can get used to it. Your child's teacher and therapists can help you learn to use three-finger jaw control correctly.

In order for your child to eat better, he should learn how to take the food off the spoon with his lips. If he doesn't do this by himself, there are a few things you can do to help him. First of all, make sure he is sitting in the right position for eating. Second, use a small spoon, especially if he is small.

Once you put the spoon in his mouth, wait awhile to see if he will use his lips to take the food off. If he doesn't, you can lift the spoon up as you pull it out of his mouth so that his top lip scrapes the food off the spoon. Do not scrape the food off the spoon with the child's teeth.

A *tongue thrust* is a reflex which causes the tongue to push forward and out of the mouth. If your child has a tongue thrust, it is difficult to put food into his mouth and keep it there. Do not try to put a spoon into his mouth when his tongue is sticking out. Here are some things that might help if your child has a tongue thrust:

1) As you put food into your child's mouth, press down on the center of his tongue with the spoon.

2) Try putting the spoon in at the side of his mouth, instead of directly in front.

3) "Walking the tongue back" can help get food into his mouth. Use a rubber-coated spoon without food on it to do this. Starting at the tip of the tongue, push down and back. Do this two or three times, moving toward the middle of the tongue each time. This should help the tongue move back into the mouth. As soon as you have finished, and your child's tongue is no longer sticking out, put the spoon with the food on it into his mouth.

If your child has trouble swallowing, three-finger jaw control may help to hold his head in the right position for swallowing. Give him his favorite pureed food to make him want to swallow, and stroke his throat with either an upward or downward motion.

When your child is drinking, it is important for him to close his lips on the edge of the cup so that the liquid will stay in his mouth. You can use three-finger jaw control to help him do this. There should be enough liquid in the cup so that your child does not have to tip his head backward to drink it. Position his body so that his head is tipped slightly forward—this will make it easier for him to swallow. A thin liquid may be hard for him to drink. A thicker liquid, such as tomato or apricot juice or a milkshake, will not leak out of his mouth as easily. If your child drools, don't use milk to teach him to drink because it will cause him to drool more.

Give him small sips at first to keep him from gagging or choking. Place the edge of the cup in back of the upper lip. This will keep him from biting the cup which will interfere with his drinking.

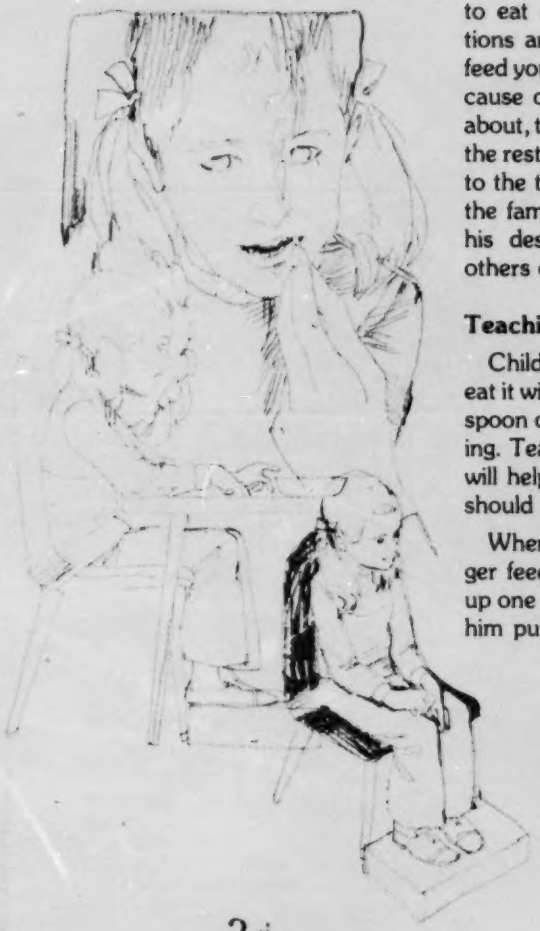
A *bite reflex* can make a child bite down too hard on anything that is placed in his mouth, such as a spoon or cup. If your child seems to do this, it may help to rub his gums before feeding him. You should rub on both sides of his gums, not in the front. Metal spoons often set off the bite reflex when they hit a child's teeth. So, it may help to use a rubber-coated spoon.

When your child is able to take food off of the spoon with his lips and swallow it fairly well, he may be ready to start chewing solid food. You should begin with foods like green beans, cooked carrots or french fries because they are easy to chew.

There are things you can do to help your child chew. Once again three-finger jaw control will help control his jaw while he is eating. You can use it to keep his mouth from opening too wide before he takes a bite. And you can use it to help him keep his mouth closed while he chews the food. As part of chewing, your child will also need to learn how to shift food back and forth inside his mouth with his tongue. This back and forth motion is necessary to chew most solid foods. You can help your child learn to do this by putting the food into his mouth from the side instead of the front.

As your child's chewing improves, give him foods that are harder to chew. Crunchy foods, such as cereal or potato sticks, may make him want to chew so that he can hear the "crunch" when he bites down. That "crunch" is his reward. It lets him know that he is doing a good job of chewing and will make him want to chew more.

Noise or interruptions during mealtime may make your child too excited to eat. Then it may be hard to work with him on new things like three-finger jaw control. So, when you begin to help your child with his chewing or swallowing, try to feed him in a quiet place. As he learns to chew and swallow and needs less help, he will probably be able to eat even when there are interruptions and some noise. If you want to feed your child away from the family because of the problems we have talked about, try feeding him a little earlier than the rest of the family. But then bring him to the table so he can enjoy being with the family at mealtime. He could have his dessert or some fruit while the others eat.



Teaching him to feed himself

Children will usually pick up food and eat it with their fingers before they use a spoon or fork. This is called finger feeding. Teaching your child to finger feed will help him learn how much food he should put in his mouth at one time.

When you begin to teach him to finger feed, be sure that your child picks up one piece of food at a time. Don't let him put a second piece of food in his

mouth before he finishes chewing the first. You can begin training him to do this by putting one piece of food on his plate at a time. As he learns to eat one piece of food before reaching for another, you can put more and more food on his plate.

As your child learns to finger feed, you can begin teaching him to spoon feed himself. To begin with, help your child to bring the food to his mouth by moving his hand with your own hand. As he begins to lift the spoon himself, you should give him less help. For example, instead of moving his hand with your hand, you would just move his wrist, then his arm and then his elbow. As he starts to get better at feeding himself, show him this makes you happy. This will reward him and will make him try harder.

Use your child's favorite foods when you begin to teach him spoon feeding. As he gets better at it, begin to feed him more foods that are good for him, even though they may not be his favorites. To make spoon feeding easier, try to use foods which stick to the spoon: cooked cereal, rice pudding, mashed potatoes, cream cheese, junior baby foods, desserts like mashed bananas or instant pudding, or any soft pureed foods. As his spoon feeding improves, use thicker foods. For example, you can add oatmeal cereal or potato flakes to make the puree thicker.

Reading List

If you would like to learn more about feeding, you might want to read the following:

Bensberg, G.J. (Ed.). *Teaching the mentally retarded: A handbook for ward personnel.* Atlanta: Southern Regional Education Board, 1966.

Bockley, J. & Miller, G. Feeding techniques with cerebral palsied children. *Phisiotherapy,* 1971.

Bureau of Public Health Nutrition. *A guide for feeding children with cerebral palsy.* California State Department of Public Health, 1966.

Finnie, N.R. *Handling the young cerebral palsied child at home.* New York: E.P. Dutton & Co., 1975.

Robinault, I. (Ed.). *Functional aids for the multiply handicapped.* Hagerstown, Md.: Harper & Row, 1973.

Virginia State Department of Health, Bureau of Crippled Children. *A helpful guide in the training of a mentally retarded child.* Richmond, Va.: 1968.

Watson, L., Jr. How to use behavior modification with mentally retarded and autistic children: Programs for administrators, teachers, parents and nurses. Columbus, Ohio: *Behavior Modification Technology,* 1972.

DRESSING

Before you try to teach your child how to dress himself, it may help to talk to his teacher or therapists. You can work with them to make sure that the way he is taught to dress at home is similar to the way he is taught in school. This will keep him from becoming confused and will help him learn faster.

Correct positioning will help to keep your child relaxed. If he is relaxed, it will be easier for you to dress him and easier for him to learn to dress himself. Remember that your child will try harder if you give him rewards. So show him that you are pleased when he tries—even if he doesn't do things just right.

In this section there is information on the type of clothing you can use for your child, on ways to make dressing your child easier, and on how to help your child learn to dress himself.

Clothing

Try to dress your child in the same kind of clothes worn by other children his age. Simple styles are easy to wash and iron. Try to choose a material that will wear well and that allows your child to move easily.

Sometimes you will have to make changes to clothes to make it easier for your child to learn to dress. For example, you may need to replace small buttons with large ones when you teach him buttoning. They should be at least as big as a nickel, flat and sewn on to stand out a little bit from the material. Since zippers can be hard to use, you may want to add a cloth loop or a metal ring to the end of a zipper to make it easier for your child to hold and pull. Use elastic waistbands instead of belts on pants and skirts. The elastic makes it easier to pull off and pull on the clothing.

You might also want to think about using Velcro tape instead of zippers. Velcro is simple to use when it is sewn on to clothes. Just press both pieces of the tape together to close them, and pull them apart to open them.

If your child wears leg braces, choose pants for him which are loose enough to fit over his braces. If there are zippers on the inside leg seams, the pants will be easier to put on over the braces. Also, it may help to line the inside of the pants with extra cloth to keep them from wearing out when they rub against his braces.

If your child uses crutches, sew pieces of cloth under the arms of shirts or blouses to keep them from wearing out. Shirts with longer shirttails will stay tucked in.

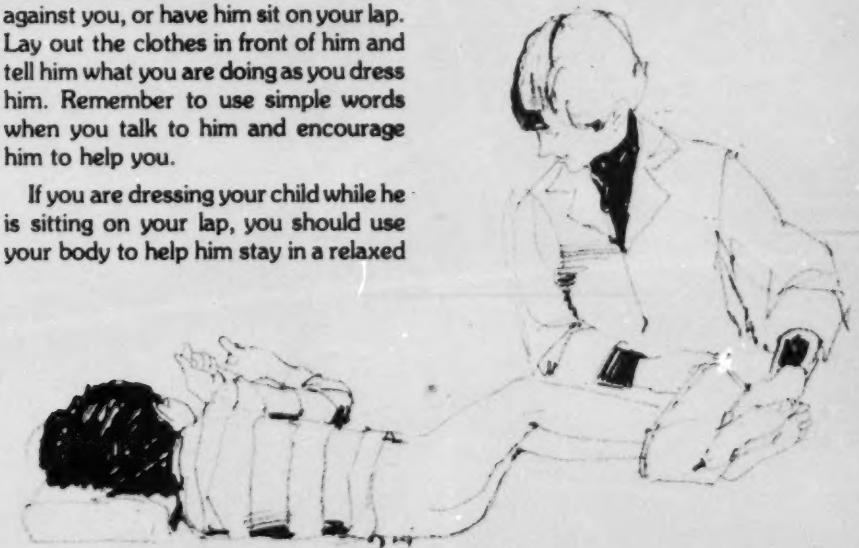
If you have an older child who needs diapers, you will want to use large, contour type diapers which absorb well but don't have much bulk between the legs. You can get sewing patterns for them from the United Cerebral Palsy Association, 66 East 34th Street, New York, N.Y. 10016.

Dressing your child

Dress your child in a sitting position whenever it's possible. In this position, he will be easier to handle and will have more of a chance to see what is going on. Let him sit on the bed and lean against you, or have him sit on your lap. Lay out the clothes in front of him and tell him what you are doing as you dress him. Remember to use simple words when you talk to him and encourage him to help you.

If you are dressing your child while he is sitting on your lap, you should use your body to help him stay in a relaxed position. To do this, put your knees between the child's legs to hold them apart. If he pushes his body backwards, use your body to keep his head bent forward.

If your child is too heavy to hold in a sitting position, you may want to dress him lying on his side or lying on his back. You can try both positions to see which one works best for your child. These positions keep your child from becoming so stiff and it will be easier for you to bend his arms, legs and hips. If you place him on his back, use a pillow to



raise his head and shoulders a little. This will bring his arms forward and will make it easier to work with them.

Whatever position you dress him in, lay out your child's clothes at arm's length before you start to dress him. That way, you won't have to get up once you start dressing him.

If he becomes tense while you are dressing him, wait for him to relax before going on. Sometimes gentle rocking and rolling can help a stiff child to relax.

If you need to bend your child's arm to get his hand into the sleeve of his clothes, move his arm from the elbow rather than his wrist. Bending his arm this way will keep it from getting stiff and will make it easier to get his hand into the sleeve.

And if you need to bend his leg to get his foot started into his pants, move his leg from the knee rather than the ankle. This will keep his leg from getting stiff and will make it easier for you and him to put his leg into his pants.

You can put a shoe on your child's foot more easily if his leg is bent and if his foot is bent upward to help the foot relax. If your child's toes curl, you will have trouble putting his shoes on. In this case, push down on top of the foot until his toes uncurl. If you try to pull the toes open, they may just curl more tightly.

When diapering your child, bend his legs at the knees to place the diaper under his bottom. If you try to lift both of his legs, he may become stiff and this will make it hard for you to diaper him.

Teaching dressing

When teaching your child to dress, you will find that it is helpful to use clothes that are one or two sizes too large. Extra roomy clothes make it easier for the child to slip into sleeves or pants legs.

Use brief instructions when you are training your child. Usually two or three words—like "put on coat"—are enough. Try to use the same words each time, so that your child doesn't get confused.

You should give your child lots of chances to practice his dressing. Try to teach him how to dress by breaking the activity into small steps. Start with a step you know he can do, like taking his arm out of a sleeve. It is important for him to have success quickly so that he will keep on trying.

Don't push your child to move too fast when he is trying to dress himself. Let him try over and over again, even when he makes mistakes. Give him rewards and praise when he does something right, or at least tries. Don't take over. Give him just enough help so that he knows what you want him to do. Then let him do as much as he can by *himself.*

Reading List

If you would like to learn more about dressing, you might want to read the following:

Bare, C., Boettke, E., & Waggoner, N. *Self-help clothing for handicapped children.* Chicago: National Easter Seal Society for Crippled Children and Adults, 1962.

Ferguson, W.R. *Helpful guide in the training of the mentally retarded child.* Virginia State Department of Health, Bureau of Crippled Children, 1968.

Finnie, N.R. *Handling the young cerebral palsied child at home.* New York: E.P. Dutton & Co., 1975.

Robinault, I. (Ed.). *Functional aids for the multiply handicapped.* Hagerstown, Md.: Harper & Row, 1973.

Watson, L., Jr. *Child behavior modification: a manual for teachers, nurses and parents.* Elmsford, N.Y.: Pergamon Press, 1973.

Watson, L., Jr. *How to use behavior modification with mentally retarded and autistic children: Programs for administrators, teachers, parents and nurses.* Columbus, Ohio: Behavior Modification Technology, 1972.

TOILET TRAINING

Parents have more problems with toilet training their child than with anything else they try to teach him. Toilet training can often be frustrating for the parent and the child.

When you begin toilet training your child, it is important for him to be well supported and to feel secure while he sits on the potty-chair. If he is not relaxed and is afraid of falling off the chair, it will be difficult for him to urinate and have bowel movements.

There are several things you can do to make sure that your child is supported and relaxed on the potty-chair. It may help him to relax if you rock him slowly before putting him on the chair. If he has trouble holding his head up or balancing his body, use a potty-chair with a headrest and armrests. Also make sure that his feet are on the floor or some other support.

Although you probably will be using a potty-chair for training your child, you should do the training in the bathroom. This way your child will connect being in the bathroom with urinating and bowel movements. Also, there will probably be fewer things to bother you and your child if you do the training in the bathroom. If your child is big enough, let him use the regular toilet.

Use training pants during training, instead of diapers. Training pants are easy to get off in a hurry, and your child needs to learn to push them down by himself as part of toilet training.

Your child's teacher and therapists can help you plan his toilet training program. If you work with them on the same program, it will keep your child from becoming confused and he will learn faster.

Before you begin the toilet training, it is necessary to find out if your child is ready for training. For five to ten days, keep a record of the number of times he wets and has bowel movements. Check him for wet or soiled pants every half hour. If he is dry for three half hours in a row on at least half of the days he is checked and if he doesn't have more than two bowel movements a day, he is ready for training. If his bowel movements are not solid, you should check with his doctor to see if there is a problem.

When your child is ready, you can begin the training. Take him to the toilet just before you think he is going to wet or have a bowel movement. Sometimes he may give you signs that he has to go —he might make faces, cross his legs or wiggle. Usually, however, you'll have to guess by figuring out about what time of day he urinates and has bowel movements. You can do this by looking back to the record you kept. So, for example, if the record told you that he usually had a bowel movement about 1:30, you would put him on the potty about 1:20.

The idea is that your child should be on some kind of schedule. If he doesn't go at about the same time each day, you should try taking him to the toilet once every hour. If he has to go more than every hour, you should shorten the time between trips to the toilet. When your child has an accident, change him as soon as possible. Don't let him get used to being wet or soiled. Show him the difference between wet and dry by having him touch his wet pants and having him help you change them.

When you take your child to the bathroom, stand in front of him, place your hands on his and help him push down his pants and undershorts (or help her pull up her skirt and then her panties down). Gradually, increase the amount of time he sits on the potty-chair, up to about ten minutes. Don't keep him on the potty-chair so long that he becomes upset. And don't punish him when he isn't able to do anything. Instead, keep taking him to the toilet until he urinates or has a bowel movement. And remember to reward him for his efforts.

When it's time to take your child to the bathroom, use simple words like "Go to the bathroom." Use gestures to show him what you mean. For example, point to the bathroom. Reward your child when he shows you in any way that he wants to go to the bathroom. Bit by bit, he may learn to go to the bathroom by himself or to let you know when he has to go.

Keep a record during the time you are toilet training your child. The record should show when he urinates or has bowel movements in the potty and when he has accidents. This will help you see how the training is going. Also, you can show it to your child's teacher when you are discussing his training with her.

Reading List

If you would like to learn more about toilet training, you might want to read the following:

Bensberg, G.J. (Ed.). Teaching the mentally retarded: *A handbook for ward personnel.* Atlanta, Ga.: Southern Regional Education Board, 1965.

Finnie, N.R. *Handling the young cerebral palsied child at home.* New York: E.P. Dutton & Co., 1975.

Foxx, R.M. & Azrin, N.H. *Toilet training the retarded: A rapid program for day and nighttime independent toileting.* Champaign, Ill.: Research Press, 1974.

Robinault, I. (Ed.). *Functional aids for the multiply handicapped.* Hagerstown, Md.: Harper & Row, 1973.

Virginia State Department of Health, Bureau of Children. *A helpful guide in the training of a mentally retarded child.* Richmond, Va.: 1968.

Watson, L., Jr. *How to use behavior modification with mentally retarded and autistic children: Programs for administrators, teachers, parents and nurses.* Columbus, Ohio: Behavior Modification Technology, 1972.

HYGIENE

Hygiene includes the things that keep the body clean and healthy—such as hair and skin care, dental care and washing. Of course, it's important to take care of your child's body. But it's also important to give him the chance to learn to care for himself.

If you do things regularly, your child will begin to learn what to expect at different times during the day. For example, try to always brush his teeth after breakfast, or comb his hair every morning and every afternoon at a regular time. And on days that you give your child a bath, try to do it at the same time of the day. As he gets to know when things are going to happen, he will be more relaxed when they are done.

Try to help your child with these things at a time when you won't be rushed. This will give you enough time to give him the help he needs, and to let him try some things on his own.

When you are training your child to do something, be sure you help him through each step. For each step, tell him what you want him to do by using simple sentences like "wash hand" or "dry face." Little by little, help him less and less so that he can begin to learn to do these things by himself. Remember to reward him when he does what you ask, or when he tries to help himself.

Washing

Your child may often hold his hands in fists because of his physical handicap. This can make it hard to wash his hands. Here are some things that might help you to open your child's hands for washing:

1) Make sure your child is relaxed.

2) Stroke downward on top of his hand with a washcloth.

3) Bend your child's wrist so that the palm comes down toward his forearm.

4) If his hand still won't open, straighten out his fingers one by one, beginning with the little finger.

If your child can stand or sit at the sink to wash his hands, place your hands over his and help him go through the steps for washing. Be sure he is paying attention to what is being done. When he shows that he can do any part of the washing himself, let him try. Reward him for trying.

If your child is not tall enough to reach the sink, keep a wooden box under the sink for him to stand on. You can also sew curtain rings on washcloths and towels to make them easy to hang on hooks. Another idea is to tie the soap to the sink with a string. This will keep it from falling on the floor or into the sink.

Whenever possible, wash your child in a bathtub. Not only can you get him cleaner in a tub, but bathing can be fun for him. If it is hard for your child to sit up in a bathtub, you might want to use a tub seat. This can make bathing him easier and safer. A tub seat that fits into the tub can be made from a plastic washbasket. For more information about tub seats, see the Special Equipment Section. A lawn chair for small children with a back that can move up and down can also be used in the tub. The tub seat and the lawn chair can help your child sit in a relaxed position which will make washing him easier. If you use the chair, make sure it has rubber tips on the legs to keep it from slipping.

Dental care

Regular dental care is important for your handicapped child. Cavities can lead to missing teeth. And a child with missing teeth can have problems eating and speaking correctly. Everyday home care and regular checkups with the dentist can help prevent cavities.

You should take your child to the dentist for a checkup about every four months. The dentist can show you how to brush and use dental floss to properly clean your child's teeth. He can also tell you about good eating habits. For example, the dentist will probably tell you that you should not give your child too many sweet things to eat because they can be bad for his teeth.

If possible, your child's teeth should be brushed after every meal. It is best to brush from side to side, using short movements. Also, be sure to brush where the teeth meet the gums. A small toothbrush with soft bristles is easier to move around inside your child's mouth, especially if he gags or has a tongue thrust.

If your child has trouble holding the toothbrush, add an elastic strap for him to put his hand through, or build up the handle of the brush to make it easier to hold. If your child's gums are very tender because of the medicine he is taking, he may not be able to use a toothbrush at all. If your child has this problem, you might want to use a Toothette instead of a brush. See the Special Equipment Section for more information.

Skin care

A child who has to stay in bed for a long time may get bed sores. To stop this from happening, change his position often and keep his bed dry. If your child wears braces, he may get red marks on his skin. This means that the braces do not fit. You should see your doctor about this as soon as possible.

Hair care

Your child's hair should be washed at least once a week and cut often. Cut bangs above the eyebrows. You want to be sure that his hair is short enough to keep it out of his eyes.

Reading List

If you would like to learn more about hygiene, you might want to read the following:

Burger, R.M. & Buckley, S.M. *Training for independence: A sequential program of daily living skills for the developmentally young: Volume IV: grooming and self-care skills.* Blue Bell, Pa.: Montgomery County Intermediate Unit, 1975.

Finnie, N.R. *Handling the young cerebral palsied child at home.* New York: E.P. Dutton & Co., 1975.

Greene, A. A preventive guide for multihandicapped children: Dental care begins at home. *Rehabilitation Literature,* 1970.

Robinault, I. (Ed.). *Functional aids for the multiply handicapped.* Hagerstown, Md.: Harper & Row, 1973.

Svirsky, H.S. The severely involved child: Maternal Backache. *Clinical Orthopedics,* 1966.

PART III
HOW TO FIND HELP FOR YOUR CHILD— SERVICES, EQUIPMENT AND INFORMATION

Your family is special because you have a multiply handicapped child. For example, you may need special equipment in your home. You may need special information about wills and trusts. And you may need to make special plans for next weekend's baby-sitter or next summer's vacation.

In Part III, we will be making suggestions about where to go and what to do when you need special help. This information should save you time, trouble and expense. And, it will help you to give your child the care he needs.

SPECIAL SERVICES

General Help

Montgomery County Mental Health/Mental Retardation Program

The Montgomery County Mental Health/Mental Retardation Program is the first place to turn to get help for your child. Their local office in your community is called a Base Service Unit, or BSU. The BSU can help you find out if there is a way to get money to pay for some of the cost of caring for your child. The people who work at the BSU will talk to you about any problems you may have with your child. If your child needs special kinds of help, they can help you find it. Get to know the BSU where you live as soon as possible. When you have a problem or question and don't know where to turn, call your BSU.

(Look below to find the office to call in your area.)

1. Community Counseling Services
   1314 High Street
   Pottstown, Pa. 19464
   Phone: 326-9250

   Spring-Ford Area
   MH/MR Center
   598 Church Street
   Royersford, Pa. 19468
   Phone: 948-7671

   Upper Perkiomen Community Counseling Service
   8th and Main Streets
   Pennsburg, Pa. 18073
   Phone: 679-6292

2. Penn Foundation for Mental Health
   Lawn Avenue
   Sellersville, Pa. 18960
   Phone: 257-6551

3. Community Organization for Personal Enrichment
   150 E. Butler Avenue
   Ambler, Pa. 19002
   Phone: 643-5222

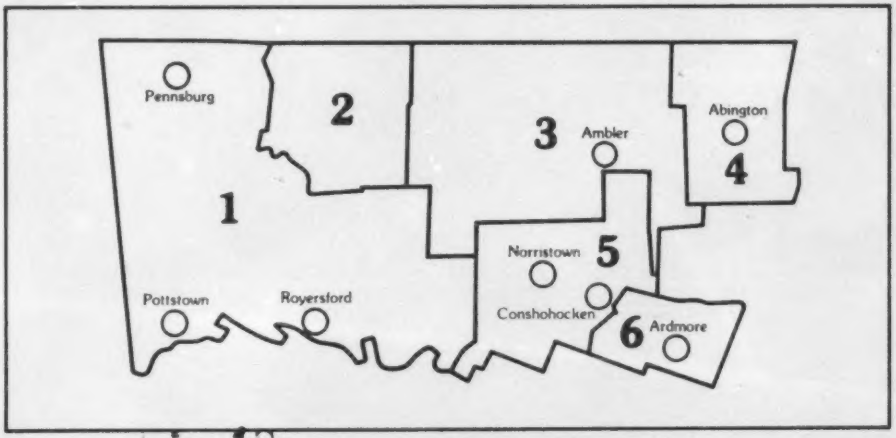
4. Abington Hospital
   MH/MR Center
   York Road
   Abington, Pa. 19001
   Phone: 885-4000, ext. 214

5. Central Montgomery MH/MR Center
   1100 Powell Street
   Norristown, Pa. 19401
   Phone: 277-4600

   Early Childhood Consultation and Education Project
   612 Fayette Street
   Conshohocken, Pa. 19426
   Phone: 825-9591

6. Lower Merion Community MH/MR Center
   3 East Lancaster Avenue
   Suite 201
   Ardmore, Pa. 19003
   Phone: 896-5340

To find the BSU closest to where you live, use this map and the list of addresses.



General Help

Montgomery County Association for Retarded Citizens (MARC)
109 East Main Street
Norristown, Pa. 19401
Phone: 272-0314

MARC is an important local group you should know about. They can give you information about schools, clinics, babysitters and other services your child may need. MARC works with the Pennsylvania Association for Retarded Citizens (PARC) and the National Association for Retarded Citizens (NARC). These organizations work for retarded children and adults at the local, state, and national levels.

Montgomery County Intermediate Unit Special Education Center
1605 B West Main Street
Norristown, Pa. 19401
Phone: 539-8550 ext. 262

The Montgomery County Intermediate Unit will give you information about educational programs and other services your child may need. Ask for the Information Specialist.

Camping

Church Council for the Exceptional Person
250 Tanglewood Road
King of Prussia, Pa. 19406
Phone: 337-2390

The Church Council has day camps for multiply handicapped children. They are Camp Beehive and Camp Busy Bee. The camping sessions are five days long and there are nine camping sessions each summer. The camping sessions begin in the middle of June and end in the middle of August. The campers do not have to be able to walk. The camping costs $35 for the five days.

It will cost another $20 if your child needs a ride. Busy Bee is at Plymouth Valley Baptist Church, 705 Germantown Pike in Norristown, and Beehive is at 50 Devon Road in Paoli.

The Church Council also has an overnight camp called Camp Donegal. This lasts for one week and is usually in August. The campers must be from 4-15 years old. The cost is $60.

The Church Council also offers a free Saturday Play program. It is held throughout the year at the Maple Glenn School, Sugartown and Poplar Roads, Devon, Pa. 19333.

Easter Seal Society Montgomery County Office
837 Sumneytown Pike
Lansdale, Pa. 19446
Phone: 699-7538

Easter Seal offers Camp Kick-a-Crutch during the summer. Older campers may have to be toilet trained, but you should call Easter Seal to find out about your child.

Easter Seal Society of Pennsylvania
Fulling Mill Road
R.D. #1
Middletown, Pa. 17057
Phone: (717) 939-7801

Easter Seal has an overnight camp called Camp Harmony Hall. The camp is on Fulling Mill Road, R.D. #1, Middletown. There are a couple of two-week camps during the summer. The cost is $160 for two weeks. Campers do not have to be toilet trained.

Ken-Crest Residential Center
Route 29
Mont Clare, Pa. 19453
Phone: 935-1581

Ken Crest offers overnight summer camping for up to 12 days. Campers must be at least 8 years old, able to walk and toilet trained. The cost for camping is approximately $250.

Ken-Crest also can take care of your child any time of the year if you have to go away. The cost is $25 per day.

Parent Groups

Parent Group of the Montgomery County Intermediate Unit Special Education Programs for the Physically Handicapped/ Multiply Handicapped/ Trainable Mentally Retarded
1630 West Marshall Street
Norristown, Pa. 19401
Phone: 539-8550

The Parent Group gives parents a chance to find out about their child's school. It also helps them learn what they might do to get help for their child. If you have a handicapped child, parent group meetings will give you a chance to talk to other parents who have handicapped children.

Parent Network
2425 North 59th Street
Philadelphia, Pa. 19131
Phone: Parent Network Hotline
642-9292

The Parent Network is made up of parents of handicapped children. They will help you find doctors, dentists and other help for your child.

Care and Training for Retarded Adults

Developmental and Activities Center (DAAC)
Contact: MARC
109 East Main Street
Norristown, Pa. 19401
Phone: 272-0314

The Developmental and Activities Center (with workshops at Glenside, Kulpsville, Norristown and Pottstown) helps families who have retarded adults living with them. DAAC will teach retarded adults how to take care of themselves and to work in a sheltered workshop. If you are taking care of a retarded adult and have to go away, they will help you find someone to take care of the retarded person while you are gone.

Developmental Enterprises Corporation (DEC)
600 Markley Street
Norristown, Pa. 19401
Phone: 277-3222

The Developmental Enterprises Corporation is a sheltered workshop, providing job training for retarded and physically handicapped adults.

Counseling and Help with Family Problems

Planned Parenthood Association
1402 Spruce Street
Philadelphia, Pa. 19102
Phone: 732-5880

50 East Chestnut Street
Norristown, Pa. 19401
Phone: 279-6094

64 North Hanover Street
Pottstown, Pa. 19464
Phone: 326-8080

Bryn Mawr Hospital
Bryn Mawr, Pa. 19010
Phone: 527-0600

Planned Parenthood will give you advice about sex and family planning. The Philadelphia office also offers courses and programs for groups.

Family Service of Montgomery County
One Plymouth Meeting —Rm. 600
Plymouth Meeting Mall
Plymouth Meeting, Pa. 19462
Phone: 825-1520

201 S. Broad Street
Lansdale, Pa. 19446
Phone: 368-0985

560 High Street
Pottstown, Pa. 19464
Phone: 326-1610

1603 Old York Road
Abington, Pa. 19001
Phone: 886-3636

18 Simpson Road
Ardmore, Pa. 19003
Phone: 642-5354

19 Race Street
Ambler, Pa. 19002
Phone: 542-8370

122 Ardmore Avenue
Ardmore, Pa. 19003
Phone: 896-8835

Keswick Avenue & Waverly Road
Glenside, Pa. 19038
Phone: 885-2522

Family Service will try to help you with problems you or other people in your family might have.

Home Health Care

Homemaker-Home Health Aid Service
Suite 310
650 Blue Bell West Building
Skippack Pike
Blue Bell, Pa. 19422
Phone: 542-9055

The Homemaker-Home Health Aide Service will give some home health care to handicapped children if there is an emergency in your home. The cost depends on how much money you make.

Visiting Nurse Associations

(Look below to find the one to call in your area.)

North Penn Visiting
Nurse Association
219 Race Street
Ambler, Pa. 19002
Phone: 643-2090

Community Health Association
25 East Athens Avenue
Ardmore, Pa. 19003
Phone: MI 2-7976

Visiting Nurses Association
of Eastern Montgomery County
1421 Highland Avenue
Abington, Pa. 19001
Phone: TU 4-0272

Clinic and Hospital Care

Visiting Nurses Association
of Penn Valley
220 South Broad Street
Lansdale, Pa. 19446
Phone: 885-8296

Pottstown Visiting Nurses
Association
1035 High Street
Pottstown, Pa. 19464
Phone: 326-0254

Visiting Nurses Association
of Norristown and Vicinity
1109 DeKalb
Norristown, Pa. 19401
Phone: 272-1160

Community Nursing Agency of
Upper Perkiomen Valley
6th and Dotts Streets
Pennsburg, Pa. 18073
Phone: 679-9061

Northern Chester County
Community Nursing Services
Phoenixville Hospital
Box 462
Phoenixville, Pa. 19460
Phone: 933-1263

The Visiting Nurse Association offers different kinds of medical care for your child at home. The cost depends on how much money you make.

State Orthopedic Clinic
Abington Memorial Hospital
1200 Old York Road
Abington, Pa. 19001

or

State Orthopedic Clinic
Pottstown Memorial Medical Center
High Street & Firestone Blvd.
Pottstown, Pa. 19464

Phone:
631-2280 (Norristown area)
887-2448 (Pottstown area)

The State Orthopedic Clinic will examine physically handicapped children one time at no cost. After that you will have to pay for the medical care of your child, depending on how much money you make.

Child Development Center
1605 West Main Street
Norristown, Pa. 19401
Phone: 539-6600

The Child Development Center provides diagnostic and evaluation services including Pediatrics, Psychology, Audiology, Psychiatry, Neurology, Social Work, and Physical, Occupational and Speech Therapy.

Elizabethtown Hospital for
Children and Youth
Elizabethtown, Pa. 17022
Phone: (717) 367-1161
extension 239, 249, 259

Elizabethtown Hospital offers diagnostic, medical, surgical, educational, and rehabilitation programs to babies, children and adolescents. In-patient and out-patient services are available. You can bring your child for a free evaluation to the Wednesday Clinic. The cost of other services depends upon how much money you make.

Children's Hospital of Philadelphia
34th Street and Civic Center Blvd.
Philadelphia, Pa. 19104
Phone: (215) 387-6000

Children's Hospital offers a rehabilitation program which includes evaluation, therapy, and follow-up for young children with cerebral palsy.

St. Christopher's Hospital
Handicapped Children's Unit
2603 North 5th Street
Philadelphia, Pa. 19133
Phone: 427-5000

St. Christopher's Hospital offers physical and mental health care services to children. Stimulation programs, occupational and physical therapy are available.

Information and Other Services — Local and State Organizations

American Heart Association
Montgomery County Office
716 West Marshall Street
Norristown, Pa. 19401
Phone: 275-8845

The American Heart Association can give you information about heart problems found in children.

American Lung Association
of Montgomery County
1529 DeKalb Street
Norristown, Pa. 19401
Phone: 279-6800

The American Lung Association can give you information about breathing problems children may have.

American Red Cross
826 DeKalb Street
Norristown, Pa. 19401
Phone: 272-6800

The American Red Cross will give you information and training on first aid. The Red Cross also has a babysitter training program.

Easter Seal Society for
Crippled Children and Adults
Sumneytown Pike
Lansdale, Pa. 19446
Phone: 699-7538
477-4437

The Easter Seal Society will loan equipment for physically handicapped children. It also gives information about other places that help the handicapped. Children can get physical therapy there if they are sent by a doctor.

Epilepsy Foundation of America
Pennsylvania Division
19th & Lombard Streets
Philadelphia, Pa. 19152
Phone: 732-3814

The Epilepsy Foundation of America can give you information about epilepsy. They will show movies and give talks about epilepsy to groups of parents.

Muscular Dystrophy Association
of America, Inc.
Philadelphia Area Field Office
7601 Castor Avenue, Suite 200
Philadelphia, Pa. 19152
Phone: 342-5900

The Muscular Dystrophy Association will help children and adults who have muscular dystrophy. They can tell you what muscular dystrophy is and how it can be treated.

National Foundation —March
of Dimes
Montgomery County Chapter
610 West Marshall Street
Norristown, Pa. 19401
Phone: 275-9175

The March of Dimes can give you information on financial help if you are buying a wheelchair, medicine, etc. Talk to the people at your BSU before you call the March of Dimes.

Pennsylvania Association for
Retarded Citizens (PARC)
1500 North Second Street
Harrisburg, Pa. 17102
Phone: (717) 234-2621

The Pennsylvania Association for Retarded Citzens offers booklets about retardation. PARC works for the retarded person at the state level to make sure retarded children receive proper help and education.

United Cerebral Palsy Association
of Philadelphia & Vicinity
4700 Wissahickon Avenue
Philadelphia, Pa. 19144
Phone: 842-0500

The United Cerebral Palsy Association will give you booklets about cerebral palsy. Write and ask for the "Parent Kit."

Information and Other Services — National Organizations

Dental Guidance Council for Cerebral Palsy
United Cerebral Palsy of
New York City
339 East 44 Street
New York, New York 10017

The Dental Guidance Council will send you booklets about dental care for handicapped children. They will also help you find dentists who are especially able to work with the handicapped.

Epilepsy Foundation of America
Suite 406
1828 L Street, N.W.
Washington, D.C. 20036

The Epilepsy Foundation will send you booklets about epilepsy. They will also tell you where to find help if your child has epilepsy.

National Association for Retarded Citizens (NARC)
P.O. Box 6109
2709 Avenue E East
Arlington, Texas 76011

The National Association for Retarded Citizens offers many booklets about retardation. The topics of the booklets range from life insurance to toilet training.

National Paraplegia Foundation
333 North Michigan Avenue
Chicago, Illinois 60601

The National Paraplegia Foundation tries to teach the public about treatment of spinal cord injuries by providing written information on paraplegia and quadriplegia.

United Cerebral Palsy Associations, Inc.
66 East 34th Street
New York, New York 10016

United Cerebral Palsy provides booklets on cerebral palsy and information about raising a cerebral palsied child. Write and ask for the "Parent's Kit."

U.S. Department of Health, Education and Welfare
Office of the Secretary
Secretary's Committee on
Mental Retardation
Washington, D.C. 20201

The U.S. Department of Health, Education and Welfare offers many books and booklets about the handicapped. They are also in charge of Federal Government services for the education and care of the mentally retarded.

SPECIAL EQUIPMENT

The kind of special furniture and equipment that you read about in other parts of this Guide – from wheelchairs to special spoons – can be used to help your child at home and at school.

Some of this equipment costs a lot, and this section has some money-saving ideas for you. It will suggest ways to make some of the equipment yourself. And it will also tell you about things you might have to buy and about where you can buy them.

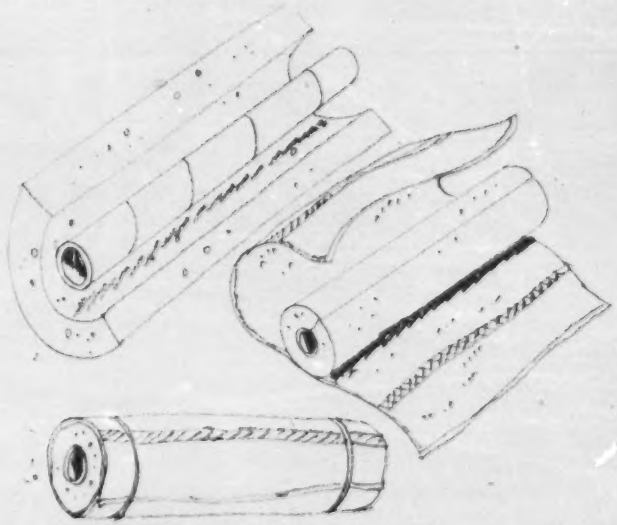
Remember to work with your child's school when you plan to make or buy special equipment for your child. The school needs the same type of equipment that you do and can give you advice about it. If you have special equipment at home that helps your child, you should let his teacher know. She might want to try to use it at school.

Supports for Sitting and Lying

Many of the things that you use to help keep your child in the correct position when he is sitting or lying can be made at home.

Sandbags are especially good for keeping your child's body in the right position. You can make one by filling a heavy-duty bag with sand and closing it tightly with strong cord or tape. You might want to try covering the bag with cloth so that it will not stick to your child's skin. If you use a cloth cover, it should have snaps so that it can be taken off and washed.

A **roll** can be made by rolling up a sheet of foam rubber. For extra strength, you can use a cardboard mailing tube as a core. The roll is then held together with tape or rubber bands. Rolls can also be covered with a cloth cover. Foam rubber can be bought in sporting goods or department stores. Instead of using a piece of foam rubber, you can roll a pillow and hold it together with tape. A towel will make a good cover for the roll. You can keep the towel in place by using rubber bands or snaps.

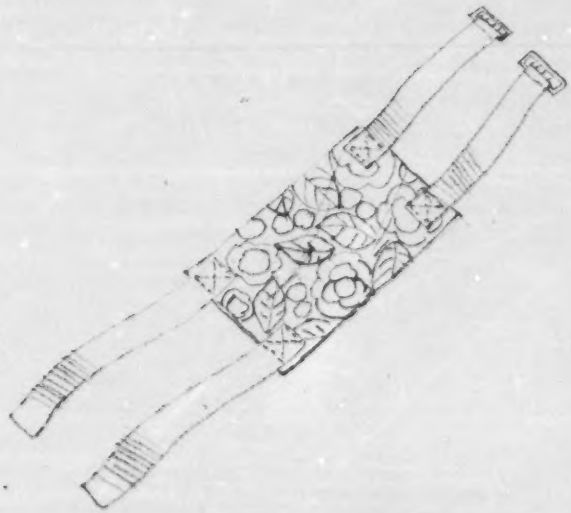


A **wedge** is very useful for keeping your child in the right position when he is on his stomach. A large, wedge-shaped piece of foam rubber can be bought at a discount department store and covered with cloth or vinyl. Or, you can make a wedge out of plywood, cover it with foam rubber and use the same type of removable vinyl or cloth cover.

If the belt you use across your child's lap does not give him enough support when he sits in a chair, an **extra wide belt** across his chest may help. You can make an extra wide belt by attaching four straps to a piece of cloth to make one wide belt. Make sure the cloth is wide enough – at least six inches. The straps can be tied or snapped around your child. You can buy the straps at hospital equipment stores.

Chairs

Learning to sit correctly is very important for your child. You should be sure that your child sits in a chair that is the right size and will give him enough support. If a chair isn't the right size, there are certain things you can do to make it fit him better. For example, if the chair seat is so large that your child's knees don't bend at the edge of the seat, you can place a firm cushion or padded board behind him. This will move him forward and allow his knees to bend over the seat of the chair as they should. If the seat is too wide, a cushion or a sandbag can be used to make it narrower. If the child's feet do not reach the floor, place a box or blocks of some kind under his feet to give them support. If his head falls back, cushions or pillows should be placed behind it for support.



Besides regular chairs, there are other things you can use as chairs. Things like rubber inner tubes, heavy cardboard boxes, "corner chairs," and beanbag chairs make good chairs. They let your child sit in a different position than he does in a regular chair. Changing his position by letting him sit in different chairs will keep him from getting stiff. Also, he might enjoy sitting on the floor where he can be with other children.

A **rubber inner tube** can be used as a chair for your child. He can sit comfortably in the center of the inner tube if you use pillows or sandbags to prop him up. If you don't have an old inner tube around the house, you can buy one at an auto supply store.

A **heavy cardboard box** can also be used as a chair for your child. The box should be small enough to hold him up in a sitting position. A pillow should be used to support his neck and back. Cut down the front and sides of the box so that he can see what is happening around him. Use masking tape over the cut edges to make them strong and smooth.

You may be able to build a **corner chair** at home out of plywood. Round off one corner on three pieces of plywood. Nail or screw the three pieces together to make the corner seat. Make sure that the base of the seat is large enough so that your child cannot tip it over. Add a strap to give him support if necessary.

Beanbag chairs are hard to make, but you can buy them at most department or furniture stores. They are useful because they can be pushed into the shapes your child needs to support his body.

Wheelchairs

Wheelchairs make it easier to move your child. And they give his body support, which is important.

Wheelchairs can be bought through hospital equipment stores, but before buying one, think about these points. The wheelchair should:

1. Help him to do as much for himself as possible.
2. Be sturdy enough for inside or outside activities.
3. Be lightweight and easy to fold up.

4. Have brakes and seatbelts.

5. Have removable parts which can be easily cleaned or replaced when broken.

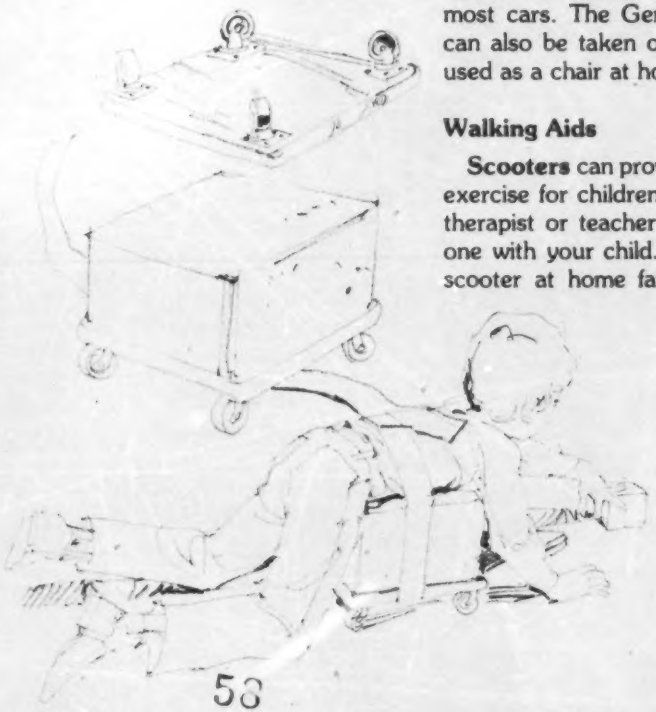
6. Have a vinyl seat for easy cleaning.

7. Be one that can be repaired nearby.

Always try out a wheelchair before you buy it. Sit your child in it to see if it's the right size. Pull his hips back so that he is resting on his bottom when he sits, and then look to see if his knees bend over the edge of the seat. Check to make sure his feet are flat on the footrests and his arms are resting comfortably on the armrests. If all of these points check out, the chair is probably the right size for your child. If at all possible, also have your child's therapist or teacher look at the chair.

There are attachments you can add to a wheelchair to give your child's body more support. For example, an adjustable headrest might help your child hold his head up. Also, if you put a tray on your child's chair, it will give him a place to rest his arms and play with his toys.

The doctor or therapists may decide that a regular wheelchair will not work for your child. He may need one that tilts back or is more adjustable than a regular wheelchair. **Relaxation chairs** are not really wheelchairs, although they do have small wheels and can be rolled around the house. They can be used in an upright position or tipped back. You can also adjust the depth of the chair seat and the height of the footrest.



58

Car Seats

It is important to have a **carseat** that keeps your child safely in his seat while the car is moving. Both General Motors and Ford dealerships sell carseats which are for small children. The GM Loveseat is one of the better seats for multiply handicapped children. It is made of padded plastic and will fit in most cars. The General Motors seat can also be taken out of the car and used as a chair at home.

Walking Aids

Scooters can provide good crawling exercise for children. Ask your child's therapist or teacher if you should try one with your child. You can make a scooter at home fairly easily. Attach

four furniture casters to a square or rectangular piece of plywood. (You can buy the casters in a hardware store.) Then glue or tack a block of foam rubber to the top of the plywood so that your child can lie on it comfortably. The scooter should support your child's body from his chest to just below his waist. It should be the right size so that he can use his arms and legs freely to move himself around. If you don't want to build the scooter yourself, you can buy one from a hospital equipment store.

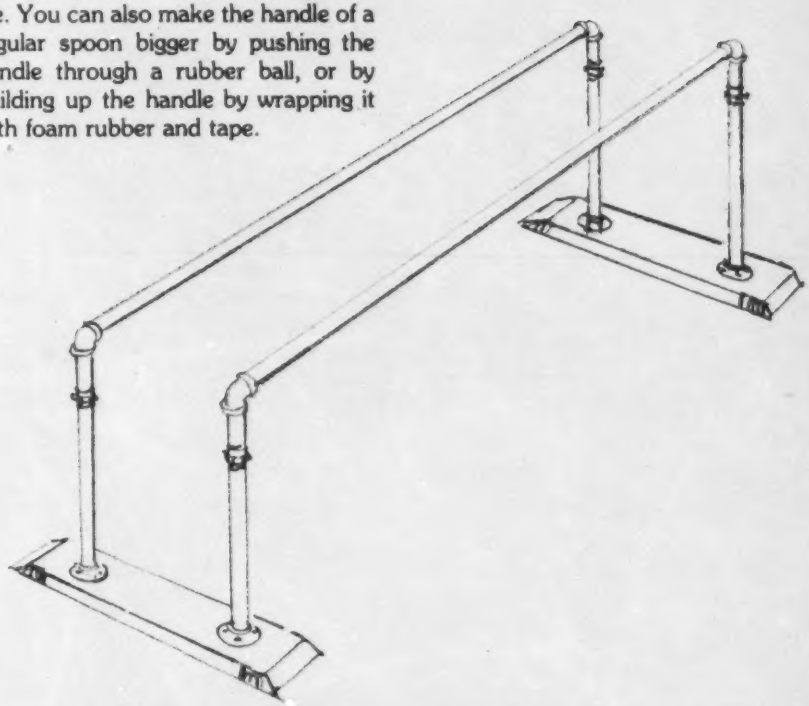
Stand-in tables provide back, head and arm support for children who are learning to stand. By using the stand-in table, your child learns to put weight on his feet and how to balance himself. Stand-in tables can be bought in hospital equipment stores.

Walking parallel bars help children who are learning to walk. The child can hold on to the two bars as he practices walking between them. You may be able to make parallel bars at home out of iron pipe. There are directions for making the bars in a book by Isabel Robinault, *Functional Aids for the Multiply Handicapped* (Hagerstown, Md.: Harper & Row, 1973). Also, you can buy parallel bars from a hospital equipment store.

Eating Aids

A **rubber-coated spoon** will help you feed a child who has a bite reflex or tongue thrust. You can buy one in the baby section of a department store.

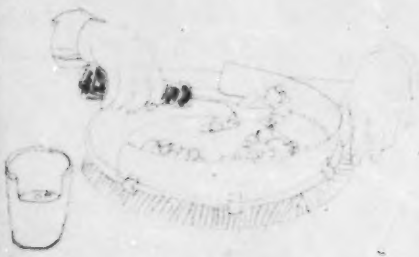
Your child may have trouble holding his spoon in his hand correctly while he is eating. If this happens, you should try to buy a spoon with an extra large handle. You can also make the handle of a regular spoon bigger by pushing the handle through a rubber ball, or by building up the handle by wrapping it with foam rubber and tape.



Your child may push a lot of food off his plate while he is eating. If this is true, you can buy plates with built-up edges to keep the food from falling off. You can also buy a **food guard** that hooks around the edge of the plate and helps keep the food on it. Most of these guards are about one inch high and are made of stainless steel.

To keep a dish from falling off the table, you can use a **non-slip placemat** or a **suction holder.** The placemats are made out of plastic material with a non-slip surface. The suction holders have a soft rubber base with suction cups on each side that hold the dish to the table.

Special spoons, forks, plates, food guards, placemats and suction holders can all be bought in hospital equipment stores.



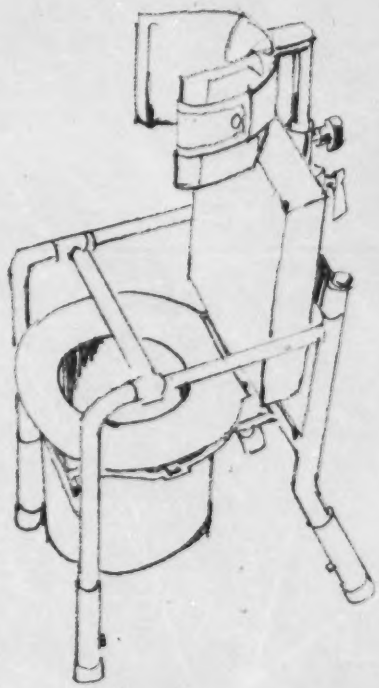
There are many special **nipples** and **drinking aids** you can buy to help your child. For example, the Nuk-Sauger Nipple helps children who have difficulty sucking and swallowing. Two aids for bottle-feeding are the Sit-N-Sip Straw or the Sit-up Straw. These straws are pushed into the bottle and let the child sit up to suck. Some of these drinking aids can be bought in food stores or drugstores. For others, you will have to go to a hospital equipment store.

Toilet Training Aids

There are many different kinds of **potty-chairs.** The plastic and metal ones are easier to clean than the chairs made of wood. Plastic potty-chairs can be bought at a local department or toy store. There are special potty-chairs for physically handicapped children. They have arm rests, footrests, headrests and seatbelts which can help your child sit the way he should on the chair. You can buy these at hospital equipment stores.

If you are toilet training your child, you may want to use something that lets you know when he has wet himself. There are **training pants buzzers** which go off when a child has wet. One brand is called Pants Alert.

There are also **toilet buzzers,** such as Potty Alert, which will buzz when your child has used the toilet. The buzzer lets you know it is time to reward your child for using the toilet correctly. The Potty Alert can be taken off the toilet and cleaned. Both the Pants Alert and Potty Alert can be bought in hospital equipment stores.



Clothing

If your child falls often, you will want to use a **safety helmet** to protect his head. You can buy these helmets at hospital equipment stores. They come in several sizes, so make sure you buy one that fits correctly.

Incontinent pants are padded waterproof underpants that will help protect your child's clothing if he is not toilet trained. You can buy them at hospital equipment stores and drugstores.

Buttons or zippers may be hard for your multiply handicapped child to use. If this is the case, a cloth fastening called **Velcro tape** can be used. You sew a piece of tape on each side of the clothing. Then, the clothing can be opened or closed by pulling the pieces apart or pushing them together. There are different types of Velcro tapes—some pull apart more easily than others. This allows you to make the fastening as easy or as difficult to open as you want.

Hygiene Aids

If your child has trouble holding a **toothbrush,** try to make the handle bigger. You can make the handle bigger by wrapping tape around it as you did with the spoon handle. An elastic or Velcro strap can also help the child who has difficulty holding on to the handle.

A **Toothette** can be used as a substitute for a toothbrush for children who have tender gums. Instead of stiff bristles, it has a soft sponge tip. The Toothette can be thrown away after use. Don Hare Supply Company (Box 176, Skippack Pike, Skippack, Pa. 19474) sells the Toothettes.

A **flexible shower hose** can help you reach those hard-to-wash places on your child. It can be particularly helpful if your child has to lie in the bathtub or sit in a special bathtub seat. You can buy these at local hardware or department stores.

A **tub seat** can help to support a child who has difficulty sitting up in the bathtub. You can buy tub seats at hospital equipment stores. Or you may be able to make a tub seat out of a plastic laundry basket. There are directions for making the seat in a book by Isabel Robinault, *Functional Aids for the Multiply Handicapped* (Hagerstown, Md.: Harper & Row, 1973).

Hospital Equipment Stores

The following is a list of some of the hospital equipment stores in the Montgomery County area. If the item you are looking for is not in stock, the store will order it for you.

AACOMED
4012 Ridge Avenue
Philadelphia, Pa.
223-8000

Accurate Home Medical Service
208 Old York Road
Jenkintown, Pa.
886-9238

Accurate Home Medical Service
8004 West Chester Pike
Upper Darby, Pa.
789-5220

Ascher Surgical Supplies
1141 Bustleton Pike
Feasterville, Pa.
355-2710

Delcrest
Catherine & Street Roads
Warminster, Pa.
675-4444

General Medical
Knights Road Industrial Park
3190 Tucker Road
Cornwells Heights, Pa.
638-9700

Myers Drug Stroe and Myoderm
Medical Supply
328 and 322 DeKalb Street
Norristown, Pa.
272-8660

North Penn Medical Surgical Supply
9 North Mitchell Avenue
Lansdale, Pa.
855-3545

Schuman's Medical Equipment Division
Schuman's Drug Centre
Second & Broad Streets
Lansdale, Pa.
855-1104

If an item cannot be bought from a local hospital equipment store, you may want to order it through the mail. One company that sells many of these things is J.A. Preston. There is a $3.00 service charge for orders under $50.00. You can write or call J.A. Preston, 71 Fifth Avenue, New York, 10003. Telephone: 212-225-8484.

BABYSITTING

This section will help you find a babysitter who is used to working with handicapped children. When the babysitter comes to your house, you should have certain information ready for her. We have included suggestions on what kinds of information you should give her.

Finding a Babysitter

The Montgomery County Association for Retarded Citizens (MARC) runs a training program for babysitters called Time-out Training. This program trains babysitters to take care of handicapped children. Call MARC (272-0314) to get a list of people who have taken the course.

Often, other parents of multiply handicapped children will know good babysitters. You can meet other parents by joining parent groups at your child's school or MARC. Also, you and other parents of multiply handicapped children can take turns babysitting.

There may be teenagers in the neighborhood who would be interested in learning how to care for handicapped children. Perhaps you can get them to attend the MARC training program.

Sometimes the Base Service Unit can help you find a babysitter. If you need to be away from your child for more than a

day, call your BSU and ask for help. Be sure that you ask for respite care and make it clear how long you will need this help. Call several weeks before the time when you will need this help.

Information for the Babysitter

When the babysitter comes to your house, have the information she will need ready for her. Fill out a form like the one we have suggested here —"What a Babysitter Should Know." It will tell your babysitter what special things she needs to know and what she must do in an emergency. It is a good idea to have one copy of the form in your child's bedroom and another downstairs near the phone.

WHAT THE BABYSITTER SHOULD KNOW

Emergency Information

Our name _____ Child's name _____

Home address _____ Phone # _____

WHERE WE WILL BE: _____
(name, address, phone #)

If you can't reach us, call _____
(name, address, phone #)

Sickness: Call me.

_____
(special instructions)

IF CHILD IS SICK OR HURT: Call Doctor _____
(name & phone #)

or Doctor _____
(name & phone #)

If you can't get a doctor, call Ambulance at _____
(phone #)

or Police at _____
(phone #)

Call Mrs. _____ at _____
(neighbor) (phone #)
Then call me.

Fire: Get child out of house. Call Fire Department at _____
(phone #)

POLICE: _____
(phone #)

Special Instructions

Medicine: _____
(Drug) (How much) (when to give)

_____
(Drug) (How much) (when to give)

Meals: _____
(Type of food) (When) (Restrictions)

_____
(Feeding methods)

Toileting: _____

Sleep: _____
(Time for bed) (Special Instructions)

Play: _____
(Where) (Toys) (Avoid)

Other Instructions: _____

_____

My Child's Favorite _____
(Activity) (Food) (Other)

64

TRANSPORTATION

Parents of multiply handicapped children can get a special automobile license plate. With this plate, you can park in spaces marked as "Handicapped Parking Only." You may also be allowed to park in some "no parking" areas for up to 90 minutes but you'd better check with the local police. There is no extra charge for this special license plate. Write to:

Department of Transportation
Bureau of Motor Vehicles
Special Tag Unit - Room 111
Harrisburg, Pa. 17122

Moving your child from the car to the house may be difficult if you can't find a nearby parking space. If it is hard to find a parking space on the street near your home, speak to your local police. It may be possible to have signs put up in front of your house that will keep other cars from parking there.

Your child may need help to sit safely in a car. You will find the "GM Loveseat" helpful for small children. It is approved by the National Safety Council. You can buy it from General Motors dealers. If your child is older, you may find a harness helpful in keeping him in place. You can buy a harness at a store such as Sears. If your child has a chest or breathing problem, you should talk to his doctor or physical therapist before buying a harness.

The local Base Service Unit (BSU) should be able to give you information about public transportation that your child can use. They may be able to tell you about special bus and taxi services for the handicapped.

The BSU may also help you pay the costs of transportation for your child. For example, if you need a cab to take your child to the doctor, the BSU may pay the cost. How much they pay depends on how much you are able to pay.

It is also important for you to know what services your local ambulance company offers. For example, you should know if they will come to your house if you have to call in an emergency. Some ambulance services will only come if they are told to by a doctor.

INCOME TAX DEDUCTIONS

The Internal Revenue Service allows income tax deductions for some of the expenses of caring for your handicapped child. Make sure you take all of the deductions you should receive. One way to do this is to keep a careful record of all the money you spend in caring for your child. This should include:

1. The name and address of the people to whom the payment was made.
2. The date of the payment.
3. The amount of money paid.
4. The reason for the payment.

When it comes time to file your tax return, use these records to figure out your deductions. A letter from your child's doctor telling about your child's condition should be attached to your return. Mail a copy of this with your tax return and keep a copy with your cancelled checks and bills.

You can deduct the cost of:

1. Medical and dental treatment. This includes what you pay the doctor and dentist and the cost of things like eye examinations, hearing tests, X-rays, medicine, vitamins, special foods prescribed by the doctor, etc.
2. Special schools or sheltered workshops, if the main purpose is to help handicapped children. This can include the cost of tuition and room and board.

3. Special evaluations and training. This includes the cost of psychological tests, and special instructions or training, such as speech instruction.

4. Transportation of your child to and from special schools and institutions, hospitals and doctors offices. This can include the cost of taxis, buses and trains. Or, if you drive him in your own car, you may also deduct a certain amount per mile plus the parking and toll fees. Call the Internal Revenue Service to find out how much you can deduct.

5. Medical insurance. Call the Internal Revenue Service to find out how much of the cost of medical insurance you can deduct.

6. Special equipment, if the doctor says that your child needs it because of his handicap. This includes eyeglasses, hearing aids, crutches, braces, wheelchairs, air-conditioning for children with asthma and other types of equipment for the home or automobile. You can deduct the cost of putting in special equipment such as the air-conditioning. Disposable diapers and diaper service are also deductible.

7. Child care. If you are divorced, widowed or married to a disabled person, and if you are employed, you may deduct part of the cost of help you hire to care for your child. Check with the Internal Revenue Service for the latest information.

For more information about tax deductions, write or call for the following booklets:

"Checklist of Medical
Expense Deductions"
United Cerebral Palsy Association, Inc.
66 East 34th Street
New York, New York 10016

"Facts You Should Know About Tax Deductions for Your Handicapped Child"
Coordinating Council for Handicapped Children
407 South Dearborn
Chicago, Illinois 60605

"Deductions for Medical and
Dental Expenses"
and
"Child Care and Disabled
Dependent Care"
Internal Revenue Service
90 West Airy Street
Norristown, Pa. 19401
277-3040
or
801 Old York Road
Noble Plaza
Jenkintown, Pa. 19406
887-4940

PLANNING FOR THE FUTURE

Planning for the future is especially important for parents who have a multiply handicapped child. Who will be able to care for your child if you are not able? How will you be able to support your child when you retire?

This section has some of the answers to these questions. You will find the information helpful, but you should also seek legal or other professional help.

Much of the following information can be found in "How to Provide for Their Future," a booklet available from the National Association of Retarded Children (NARC), P.O. Box 6109, 2709 Avenue E East, Arlington, Texas 76011.

Death of Parents

In most states, there are laws that see that a child under the age of 21 will be taken care of when his parents die. But at age 21, the child is expected to be able to take care of himself. Most multiply handicapped persons cannot take care of themselves when they become adults. Therefore, the parents of a multiply handicapped child should talk to a lawyer to make sure their child will be taken care of when they die or are disabled. This should be done as soon as possible.

Wills and Trusts

The multiply handicapped person cannot handle large amounts of money or property. So the parent should not will money or property directly to the child, and should ask relatives not to do so either.

A will can be used by a parent to make financial plans for the child and to make sure that he is cared for in the future. One way to do this is to set up a "trust" for the child. Make plans for a "trust" for your child now by talking to a lawyer or bank officer.

Insurance

Life insurance on the parents' lives is one way of taking care of the child if the parents die.

There are group policies available. The National Association for Retarded Citizens (NARC) offers term insurance at group rates for the parents of retarded children. This plan is available to a parent if he is earning an income, is under 70, and is a member of a local or state unit of NARC (such as MARC or PARC).

In addition to life insurance, a parent would be wise to have family health and accident insurance. When the child is too old to be covered under the family policy (usually at age 19), it may be necessary to obtain an individual policy. In some states, a child who is still dependent upon the parents after age 19 can still stay on the family policy.

Social Security

When a parent dies or retires, a multiply handicapped child can receive Social Security payments. Any child can get these payments until he reaches 18 years of age. But a multiply handicapped child may still receive them *after* he reaches 18. He can get these monthly payments as long as his condition keeps him from "substantial gainful work" as an adult. The size of the payments depends upon how much the father or mother has paid into the social security fund. You can get information on these benefits from the social security office.

There are other programs which may provide aid to the multiply handicapped child or his family. Parents should ask about Supplementary Security Income (SSI) at the nearest Social Security Office, and about medical aid programs at the Montgomery County Board of Assistance.

Social Security Office
(Contact nearest office)
55 East Marshall Street
Norristown, Pa. 19401

614 North Easton Road
Glenside, Pa. 19038

Queen & Roland Streets
Pottstown, Pa. 19464

for all three offices
Phone: 279-9450 or TU 7-8802

Montgomery County Board of Assistance
506 West Marshall Street
Norristown, Pa. 19401
Phone: 631-2111

There are also programs of aid designed for children of Veterans who are at least 50% disabled as a result of sergice in the Armed Forces, or who have died. A Veteran's multiply handicapped child is eligible for these benefits. The nearest Veterans offices are:

Veteran's Affairs
Montgomery County Courthouse
Airy & Swede Streets
Norristown, Pa. 19401
Phone: 275-5000

Veteran's Administration
5000 Wissahickon Avenue
P.O. Box 8079
Philadelphia, Pa. 19101
Phone: GE 8-5225

Legal Help

It is important to have legal help when writing a will or setting up a trust fund. If a parent does not have a family lawyer and needs help to find one, he can get a list of lawyers from:

Lawyer Reference Service
100 West Airy Street
Norristown, Pa. 19401
Phone: 279-9660

If the parent cannot afford to pay for a lawyer, he can contact:

Legal Aid Service Division
Montgomery Bar Association
118 West Airy Street
Norristown, Pa. 19401
Phone: 275-5400